Acknowledgements

This report has been prepared under the guidance and support of the Victorian Renal Clinical Network Leadership Group (VRCN LG) and its sub-committees. In particular, the VRCN LG would like to acknowledge the contributions of the:

1. Chronic kidney disease sub-committee chaired by Professor Peter Kerr
2. Dialysis sub-committee chaired by Associate Professor Nigel Toussaint
3. Transplant sub-committee chaired by Professor Rowan Walker
4. Renal supportive care sub-committee chaired by Professor Mark Boughey
5. The many organisations and healthcare professionals that also contributed their expertise and knowledge to this document.

To receive this publication in an accessible format, please phone +61 3 9096 0510, using the National Relay Service 13 36 77 if required, or email renal.clinicalnetwork@dhhs.vic.gov.au

Authorised and published by the Victorian Government, 1 Treasury Place, Melbourne.

© State of Victoria, June 2016

This work is licensed under a Creative Commons Attribution 3.0 licence (creativecommons.org/licenses/by/3.0/au). It is a condition of this licence that you credit the State of Victoria as author.

Except where otherwise indicated, the images in this publication show models and illustrative settings only, and do not necessarily depict actual services, facilities or recipients of services. This publication may contain images of deceased Aboriginal and Torres Strait Islander peoples.


(1606002)
Foreword

Kidney disease affects approximately 10% of the global population with diabetes and hypertension being amongst the commonest causes. The increasing prevalence of such conditions in our communities suggests we are likely to see more Victorians with kidney disease requiring therapy, including those with mild disease in the community through to those requiring specialist care with dialysis and transplantation.

The Victorian Government spends over $200 million a year in the provision of dialysis services to around 3,000 Victorians and around 300 transplant procedures. There are also almost 2,900 Victorians living with a functioning renal transplant, who require ongoing clinical review, psychosocial support and immunosuppressive drug treatments.

This document sets out steps of care that provide safe and effective person centred care, and, where it exists, evidence based practice, in order to achieve equitable access and high quality care for Victorians with renal disease. Of particular importance is the emphasis on bringing together the early detection and management of chronic kidney disease with specialist intervention like dialysis and transplantation through to the end-of-life care.

Consistent with Renal directions: better services and improved kidney health for Victorians (Renal directions), the Renal Integrated Care Pathway (RICP) provides the framework for the delivery of renal services. This means providing patients with as positive an experience as is possible through the delivery of care that is respectful, appropriate and accessible. The RICP also aims to drive system-wide improvement through a reduction in unwarranted variation of care and improved patient outcomes.

A key element of the report is the five key principles that underpin the RICP:

1. person-centred care and shared decision making
2. screening and assessment
3. information and education
4. integrated care
5. access and equity.

In addition, the pathway promotes collaboration both within the renal service sector and across health care boundaries, including primary care, private practice and across clinical disciplines. The RICP is further grounded in good clinical leadership, patient and consumer participation, staff engagement, and transparency in data and accountability. Supporting the RICP is openness to innovation in clinical practice and improving service sustainability through ongoing system improvement, culture change and clinical research.

I commend this report to you and expect it to be used as an ongoing reference for renal services.

Professor Steve Holt
Clinical Lead and Chair
Victorian Renal Clinical Network.
## Contents

**Summary: renal integrated care pathway**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Steps in care for the management of people with chronic kidney disease</td>
<td>1</td>
</tr>
<tr>
<td>Steps of care</td>
<td>3</td>
</tr>
</tbody>
</table>

**Intent of the renal integrated care pathway**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>10</td>
</tr>
<tr>
<td>A better patient journey</td>
<td>11</td>
</tr>
<tr>
<td>Chronic kidney disease in context</td>
<td>11</td>
</tr>
</tbody>
</table>

**Key principles**

<table>
<thead>
<tr>
<th>Principle</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person-centred care and shared decision making</td>
<td>14</td>
</tr>
<tr>
<td>Screening and assessment</td>
<td>14</td>
</tr>
<tr>
<td>Information and education</td>
<td>15</td>
</tr>
<tr>
<td>Integrated care</td>
<td>15</td>
</tr>
<tr>
<td>Access and equity</td>
<td>16</td>
</tr>
</tbody>
</table>

**A supportive approach to kidney disease**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance care planning</td>
<td>17</td>
</tr>
<tr>
<td>Communication</td>
<td>18</td>
</tr>
<tr>
<td>Accessing external support services</td>
<td>19</td>
</tr>
<tr>
<td>Prehabilitation and rehabilitation</td>
<td>20</td>
</tr>
<tr>
<td>Consent</td>
<td>23</td>
</tr>
<tr>
<td>Pathology</td>
<td>23</td>
</tr>
<tr>
<td>Organ donation</td>
<td>23</td>
</tr>
</tbody>
</table>

**Steps in care for people with chronic kidney disease**

**Step 1: Early detection and management: CKD Stages 1 and 2**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person-centred care and shared decision making</td>
<td>27</td>
</tr>
<tr>
<td>Screening and assessment</td>
<td>28</td>
</tr>
<tr>
<td>Information and education</td>
<td>28</td>
</tr>
<tr>
<td>Integrated care</td>
<td>29</td>
</tr>
<tr>
<td>Access and equity</td>
<td>30</td>
</tr>
<tr>
<td>Suggestions for implementation</td>
<td>30</td>
</tr>
</tbody>
</table>
### Step 2: Secondary prevention and management of progressive kidney disease: CKD Stages 3a and 3b

- **Goals of care**
- **Person-centred care and shared decision making**
- **Screening and assessment**
- **Education and information**
- **Integrated care**
- **Access and equity**
- **Suggestions for implementation**

### Step 3: Preparation for CKD Stage 5 (kidney failure)

- **Person-centred care and shared decision making (SDM)**
- **Screening and assessment**
- **Renal supportive care (RSC)**
- **Information and education**
- **Integrated care**
- **Access and equity**
- **Suggestions for implementation**

### Step 4a: Treatment for CKD Stage 5: transplantation

- **Treatment options**
- **Person-centred care and shared decision making**
- **Screening and assessment**
- **Information and education**
- **Integrated care**
- **Access and equity**
- **Suggestions for implementation**
**Step 4b: Treatment for CKD Stage 5: dialysis**

- Person-centred care and shared decision making
- Screening and assessment
- Information and education
- Integrated care
- Access and equity
- Improving care for patients on dialysis
- Suggestions for implementation

**Step 4c: Treatment of CKD Stage 5: renal supportive care**

- Person-centred care and shared decision making
- Screening and assessment
- Integrated care
- Information and education
- Access and equity
- Suggestions for implementation

**Step 5: End-of-life care**

- Person-centred care and shared decision making
- Screening and assessment
- Information and education
- Integrated care
- Access and equity
- Suggestions for implementation

**References**

**Appendix A: Sustainability, technology and innovation**

- Service sustainability
- Information and communication technology (ICT) and new technology
- Data collection and performance monitoring
- Funding
- Workforce
- Research and teaching
- Environmental sustainability
<table>
<thead>
<tr>
<th>Appendix B: Five Rs of good patient care</th>
<th>93</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix C: Populations with special needs</td>
<td>95</td>
</tr>
<tr>
<td>Culturally and linguistically diverse (CALD) populations</td>
<td>95</td>
</tr>
<tr>
<td>Aboriginal renal health</td>
<td>95</td>
</tr>
<tr>
<td>Older people with CKD</td>
<td>95</td>
</tr>
<tr>
<td>People with a disability</td>
<td>96</td>
</tr>
<tr>
<td>Adolescents and young adults</td>
<td>96</td>
</tr>
<tr>
<td>Appendix D: Elements of a successful education program</td>
<td>98</td>
</tr>
<tr>
<td>Appendix E: Pathology schedule</td>
<td>99</td>
</tr>
<tr>
<td>Appendix F: Health Independence Program – key contacts</td>
<td>100</td>
</tr>
<tr>
<td>Appendix G: Acronyms</td>
<td>101</td>
</tr>
<tr>
<td>Appendix H: Glossary</td>
<td>102</td>
</tr>
</tbody>
</table>
Tables

Table 1: Key stages of CKD, intervention and management 13
Table 2: Key elements of a successful CKD education program 43
Table 3: Pathology schedule 99
Table 4: Health independence program contact information 100

Figures

Figure 1: Steps in care for the provision of care and treatment of chronic kidney disease 2
Figure 2: The well patient chronic disease model of renal rehabilitation 22
Figure 3: Steps of CKD care 25
Figure 4: Core members of the transplant MDT 52
Figure 5: Core members of the dialysis MDT 61
Figure 6: Core members of the supportive care MDT 70
Figure 7: Core members of the end-of-life MDT 80
Figure 8: Five Rs of renal care 94
Summary: renal integrated care pathway

Steps in care for the management of people with chronic kidney disease

The Renal Integrated Care Pathway (RICP) is intended to assist and guide renal service providers to deliver services for Victorians with chronic kidney disease (CKD) in a consistent, safe and evidenced-based manner that is coordinated, responsive, accessible and sustainable. Consistent with Renal directions: better services and improved kidney health for Victorians (Renal directions), the RICP is designed to improve patient decision making and coordination of high-quality care to support consistent management of the disease, and will ensure:

- improved patient outcomes
- enhanced health-related quality of life (HRQoL)
- improved patient independence
- reduced inappropriate variation in care
- improved utilisation of services.

The steps in care for people with CKD outline the key milestones in the patient journey from early detection and diagnosis, through to treatment and ultimately end-of-life care. While the steps are presented as linear in this RICP, the reality is that, for many patients, their CKD journey will be anything but linear, especially as their disease progresses and they move between treatment options. In addition, the nature of the disease means that many patients can influence their disease trajectory, especially the group whose kidney disease is a consequence of modifiable lifestyle behaviours.

Five key steps of care are described (see Figure 1). Each step and the optimal care pathway is described in more detail in this document.
Figure 1: Steps in care for the provision of care and treatment of chronic kidney disease

**Step 1**
Early detection and management of people at risk

- **CKD Stage 1**
  Population health & primary prevention

- **CKD Stage 2**
  Early detection, risk reduction & lifestyle management

**Step 2**
Secondary prevention and management

- **CKD Stage 3a**
  Risk minimisation & managing underlying causes of CKD

- **CKD Stage 3b**
  Managing complications & early treatment planning, including referral to a specialist renal service

**Step 3**
Preparation for treatment of CKD Stage 5

- **CKD Stages 4 & 5**
  Comprehensive treatment planning and decision making, pre-emptive transplant, access creation, referral to external support services

**Step 4**
Treatment
  - Transplantation
  - Dialysis
  - Renal supportive care

- **CKD Stage 5**
  Treatment initiation and ongoing management of disease, including screening and assessment for HRQoL, cognitive and functional status and symptom management

**Step 5**
Management of end-of-life care

- **CKD Stage 5**
  Planned and supported, high quality end-of-life care that minimises distress, discomfort & unnecessary symptom burden
## Steps of care

<table>
<thead>
<tr>
<th>Goals of care</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Greater community awareness of CKD and CKD risk factors.</td>
<td>• Address common risk factors for CKD, including: obesity, diabetes, hypertension CVD, cigarette smoking, aged over 60, Aboriginal and Torres Strait Islander status, family history, severe socioeconomic disadvantage and history of AKI.</td>
<td>• Improved linkages and defined referral pathways between primary care and health services, especially for screening and assessment.</td>
</tr>
<tr>
<td>• Systematic and targeted CKD screening.</td>
<td>• Targeted annual screening for people at risk of CKD.</td>
<td>• Patients at risk of CKD or early diagnosed CKD are actively supported and involved in the management of their disease, including lifestyle modification support.</td>
</tr>
<tr>
<td>• Routine and regular monitoring of populations at risk.</td>
<td></td>
<td>• Patients are benefiting from a multidisciplinary approach to care which includes partnering with other specialties, especially cardiac and diabetes services.</td>
</tr>
<tr>
<td>• Enhanced management of CKD to prevent or slow disease progression.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Step 2: Secondary prevention and management of progressive CKD: CKD Stages 3a and 3b

<table>
<thead>
<tr>
<th>Goals of care</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Prevent or slow CKD progression.</td>
<td>• Focus on identification of patients whose observed rate of decline of eGFR is likely to lead to kidney failure and the need for RRT.</td>
<td>• Patients are actively involved in the ongoing management and decision-making process regarding treatment and intervention of their CKD.</td>
</tr>
</tbody>
</table>
| • Optimise patient HRQoL by addressing poor lifestyle behaviours and comorbidities. | • Characteristics associated with progressive CKD likely to lead to kidney failure:  
  • young age  
  • consistent decline in renal function over time  
  • presence of albuminuria  
  • presence of underlying primary renal disease (such as primary glomerular diseases, diabetic nephropathy, or renovascular disease)  
  • high blood pressure  
  • development of CKD complications (such as increased serum phosphate and/or decline in haemoglobin levels). | • Patients are actively involved in the ongoing management of symptoms and modifiable lifestyle behaviours. |
| • Optimal management of complications. | • In collaboration with the patient, objectives for the treating primary care clinician and care team should be to:  
  • assess and reduce CKD and CVD risk factors  
  • diagnose and treat the cause(s) of CKD  
  • reduce risks of AKI, for example, nephrotoxic medications or volume depletion  
  • prevent/minimise complications of CKD  
  • implement strategies to delay or slow progression of CKD  
  • optimise health and quality of life. | • Patients receive regular and comprehensive assessments by their general practitioner or primary medical practitioner, including nutritional status:  
  - six- to 12-monthly for patients at Stage 3a  
  - three- to six-monthly for patients at Stage 3b. |
| • Timely referral to specialist renal care. | | |

### Step 3: Preparation for CKD Stage 5

<table>
<thead>
<tr>
<th>Goals of care</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
</table>
| • Timely, appropriate and informed referral to specialist nephrology care.  
• Comprehensive assessment as the basis for formulation of a management plan, negotiation of goal setting and care plan, including treatment options. | • Provide patients with adequate information regarding all treatment options, including the advantages, disadvantages, risks and benefits of each option.  
• Patients should be managed using a MDT approach, especially for those with complex healthcare needs.  
• All patients to receive baseline screening and, where required, comprehensive assessment as per pathway guidelines. | • Assessment for possible pre-emptive transplantation is undertaken early, efficiently and without pre-conceived views as to individual suitability or preferences.  
• Relevant vaccinations and malignancy testing are completed before transplantation or dialysis start. |
### Step 3: Preparation for CKD Stage 5 (continued)

<table>
<thead>
<tr>
<th>Goals of care</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
</table>
| • An effective fast track system for ‘late presenters’, incorporating ongoing review to reduce incidence of complications.  
• Timely preparation for transplantation, dialysis or RSC. | • All patients approaching CKD Stage 5 to have:  
  - early assessment for RRT without pre-conceived views as to patient suitability or preferences to any particular treatment or modality  
  - comorbid diseases reviewed and issues addressed  
  - ACP initiated (if not already discussed), otherwise reviewed and updated.  
• Referral  
  - all appropriate patients to be referred to a specialist nephrologist or nephrology service by early Stage 4 (eGFR of < 30 mL/min/1.73 m²), or at least twelve months prior to anticipated kidney failure  
  - patients considering transplantation to be referred to a renal transplant unit at least 12 months prior to anticipated need for transplant, especially if considering a pre-emptive transplant  
  - patients choosing HD require timely referral to a vascular surgeon for the creation of their vascular access. This should be a minimum of three to six months prior to anticipated commencement of dialysis  
  - patients who present with CKD and likely to need RRT within three months (that is, late referral) to have access to an accelerated pathway of education and access creation. | • Patients are benefiting from care coordination across specialist services and primary care with a designated agent/agency to take lead role in care coordination.  
• Patients and their carers and families receive comprehensive and unbiased information regarding treatment choices and location of treatment in a timely manner.  
• Patients are given appropriate information regarding the advantages and disadvantages of each treatment option, including potential complications or side effects that may occur as a result of treatment or medication.  
• Patients should also be told why some treatment options may not be suitable for them.  
• Patients understand the likely trajectory of their disease, including a reasonable estimate of prognosis.  
• If appropriate, patients are provided with information about how they will be cared for at the end of life no matter which treatment option they choose. |

• Education  
  - formal comprehensive information and education is essential for all patients at this stage  
  - renal services to identify and address barriers to accessing education, including such things as cognitive or physical impairment, transport or financial issues, denial, psychological stressors and so on  
  - education should be individualised and consistent with the patient’s level of health literacy.
### Step 4a: Treatment for CKD Stage 5: transplantation

<table>
<thead>
<tr>
<th>Goals of care</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Timely referral to nephrology and transplant team.</td>
<td>• Kidney transplantation should be considered for all patients likely to progress to CKD Stage 5.</td>
<td>• All potential recipients:</td>
</tr>
<tr>
<td>• Early identification of all potential patients for transplantation,</td>
<td>• Clinically suitable patients should be placed on the transplant list in a timely manner as per clinical guidelines.</td>
<td>• have equity of access to transplantation regardless of point of referral and geographical location</td>
</tr>
<tr>
<td>particularly pre-emptive transplantation.</td>
<td>• Potential transplant recipients should have access to all transplant treatment options subject to clinical and psychosocial suitability and assessment.</td>
<td>• are provided with clear and unambiguous care pathways including benefits and risks</td>
</tr>
<tr>
<td>• Early identification of potential living kidney donor.</td>
<td>• All patients considering transplantation must receive education regarding benefits and risks to enable informed consent.</td>
<td>• are given an explanation of tests, procedures and results</td>
</tr>
<tr>
<td>• Early consideration of simultaneous pancreas kidney transplantation in</td>
<td>• Post-transplant assessment and monitoring requirements may include:</td>
<td>• are provided with a documented shared care plan based on patient empowerment and self-management.</td>
</tr>
<tr>
<td>suitable patients with Type 1 diabetes.</td>
<td>• monitoring allograft function</td>
<td>• Patients are supported to maintain physical and psychological readiness for transplantation. This is especially important for patients on the AOMS waiting list.</td>
</tr>
<tr>
<td>• Ongoing support for the management of medication adherence.</td>
<td>• vaccination</td>
<td>• Ideally, patients are managed by their transplant physician for the first six months post- transplant, then, providing they are stable, referred back to their general nephrologist for ongoing care.</td>
</tr>
<tr>
<td>• Early identification of psychosocial issues and lifestyle modification.</td>
<td>• routine screening for new-onset diabetes, bone disease, cancer, hypertension</td>
<td>• Regular exercise may help minimise some of the side effects of immunosuppressant medications and should form part of any post transplantation care plan.</td>
</tr>
<tr>
<td>• Management plan for donors requiring further investigations or additional</td>
<td>• monitor lifestyle related issues – obesity, smoking, drugs and alcohol and so on</td>
<td></td>
</tr>
<tr>
<td>support.</td>
<td>• sexual function and fertility</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• mental health – depression and anxiety</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• symptom burden</td>
<td></td>
</tr>
</tbody>
</table>
Step 4b: Treatment for end CKD Stage 5: dialysis

<table>
<thead>
<tr>
<th>Goals of care</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Patient is well-prepared for dialysis, including commencing on preferred</td>
<td>• All patients should be offered the choice between home and facility-based dialysis. However, home</td>
<td>• Patients receive a baseline assessment of their physical, functional, cognitive, mental health, and socioeconomic status prior to</td>
</tr>
<tr>
<td>modality and place of dialysis, with a permanent access in place.</td>
<td>dialysis should be considered as the option of first choice.</td>
<td>commencement of dialysis.</td>
</tr>
<tr>
<td>• Patient understands the risks, impacts and commitment required to</td>
<td>• Patients requiring dialysis have access to the treatment without delay.</td>
<td>• There is ongoing shared decision making between the patient and their care team to ensure timely and appropriate interventions occur</td>
</tr>
<tr>
<td>undertake dialysis treatment.</td>
<td>• Patients are supported through a combination of optimal clinical care and a program of rehabilitative</td>
<td>should treatment not meet expectations.</td>
</tr>
<tr>
<td>• Patient receives ongoing support and encouragement to maintain a healthy</td>
<td>care to enable them to live a ‘normal’ life for as long as possible.</td>
<td>• The patient’s physical and psychological symptoms are routinely and regularly assessed and actively managed.</td>
</tr>
<tr>
<td>lifestyle with best possible HRQoL.</td>
<td>• Patients should have their modality choice reviewed within three months of commencement.</td>
<td>• Patients recognised by the MDT as ‘deteriorating despite dialysis’ and therefore approaching end of life, are managed as per their ACP</td>
</tr>
<tr>
<td></td>
<td>• Should the chosen modality not be meeting patient and MDT outcome expectations, the patient should</td>
<td>and receive appropriate end-of-life care.</td>
</tr>
<tr>
<td></td>
<td>receive counselling to determine the most appropriate resolution to identified needs, including</td>
<td>• The decision to cease dialysis is a joint decision between the patient, their family and the MDT.</td>
</tr>
<tr>
<td></td>
<td>consideration of RSC.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Supporting carers as well as patients is essential.</td>
<td></td>
</tr>
</tbody>
</table>
### Step 4c: Treatment for CKD Stage 5: Renal supportive care

<table>
<thead>
<tr>
<th>Goals of care</th>
<th>Interventions</th>
<th>Outcomes</th>
</tr>
</thead>
</table>
| • RSC integrates renal, palliative care and other related services to provide:  
  • improved care for patients with CKD or on dialysis with difficult to control symptoms  
  • a better patient and family experience  
  • greater choice and autonomy around decision making regarding whether to commence or discontinue dialysis  
  • better disease control and symptom management for patients on either a supportive or dialysis pathway  
  • enhanced coordination of care for patients with both Stage 5 CKD and another life-limiting disease (for example, cancer).  
  • Those who may not be suitable for dialysis or transplantation usually have other serious illnesses as well as kidney disease which may include:  
    • severe chronic heart or lung disease  
    • severe peripheral vascular disease  
    • advanced cancer  
    • dementia.  | • RSC is presented as a valid and clinically appropriate treatment option, especially for those patients who are unlikely to benefit from other treatments.  
  • Patients on a RSC pathway may be referred to a palliative care team for management of symptoms, psychosocial and spiritual needs in line with the patient’s ACP.  
  • Patients need to be reassured that RSC is not end-of-life care and that many people will live for months or years with minimal kidney function.  
  • Patients receiving RSC must continue to receive appropriate management of their CKD as well as any other interventions that will assist in the management of their diseases.  
  • RSC should preferably be provided through a specific renal supportive care program.  | • Patients receiving RSC will continue to receive appropriate management of their CKD as well as any other interventions that will assist in the management of their diseases.  
  • The MDT will work closely with the patient, their family and carers, and other healthcare professionals to ensure that pain and other symptoms are minimised and well controlled, and that there appropriate referral for additional supports if and when required.  
  • People receiving RSC are routinely screened using a validated screening tool or suite of tools. Any identified issues are then assessed and interventions planned and activated.  
  • Patients will have their care requirements regularly reviewed and assessed by the renal MDT and the palliative care team.  
  • Renal services will provide a RSC consultancy service to support patients close to their place of residence. |
### Step 5 End-of-life care

<table>
<thead>
<tr>
<th><strong>Goals of care</strong></th>
<th><strong>Interventions</strong></th>
<th><strong>Outcomes</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients are supported to recognise that the end-of-life phase is approaching so that end of life can be planned and appropriately provided.</td>
<td>Timely recognition that the person is at the end of life to ensure that an end-of-life plan can be developed and put in place.</td>
<td>All patients have an ACP that includes clearly understood advance care directives.</td>
</tr>
<tr>
<td>Patients die with dignity in a setting of their own choice; with a jointly agreed palliative care plan built around their individual needs and preferences.</td>
<td>Access to, collaboration with, and referral (when appropriate) to palliative care services.</td>
<td>Patients and their families approaching end of life are treated with compassion, dignity and respect.</td>
</tr>
<tr>
<td>Patients have their care needs provided in a planned and agreed manner that minimises distress, unnecessary symptom burden and poor HRQoL.</td>
<td>Access to MDT within the health services and MDT meetings in which the care of people who are at the end of life is discussed.</td>
<td>Patients and their families are provided with information about what to expect over the coming days/weeks, as well as have individual patient needs addressed.</td>
</tr>
<tr>
<td>The patient’s right to withdraw from treatment that is potentially burdensome, including dialysis, is acknowledged, and such instances are worked through in a sensitive and person-centred manner by the MDT.</td>
<td>Effective communication processes between renal service providers, the person’s general practitioner, palliative care services and other community services.</td>
<td>Patients and their carers/families are informed, educated and accepting of palliative care services.</td>
</tr>
<tr>
<td></td>
<td>Access and opportunity for review of ACP.</td>
<td>Nephrologists and other key members of the care team are confident that they have the skills to recognise and appropriately manage patients who are imminently dying, including knowing when to refer to palliative care and when to implement advance directives.</td>
</tr>
<tr>
<td></td>
<td>Referral to appropriate community services for example, community care, Royal District Nursing Services or other community nursing services, community palliative care and so on.</td>
<td>All people who are imminently dying have access to an appropriate level of care and support, irrespective of geographic location, CALD, Aboriginal and Torres Strait Islander or religious status.</td>
</tr>
<tr>
<td></td>
<td>End-of-life care plan, including preferred location of care.</td>
<td>After-death care is appropriately managed in accordance with patients’ religious, cultural or spiritual requirements.</td>
</tr>
</tbody>
</table>
Intent of the renal integrated care pathway

Introduction
The Renal Integrated Care Pathway (RICP) is intended to assist and guide renal service providers to deliver services for Victorians with chronic kidney disease (CKD) in a consistent, safe and evidenced-based manner that is coordinated, responsive, accessible and sustainable. Consistent with Renal directions: better services and improved kidney health for Victorians (Renal directions), the RICP is designed to improve patient decision making and coordination of high-quality care to support consistent management of the disease and will ensure:

- improved patient outcomes
- enhanced health related quality of life (HRQoL)
- improved patient independence
- reduced inappropriate variation in care
- improved utilisation of services.

The RICP envisages a service system where:

1. There is improved kidney health within the broader Victorian population.
2. People with CKD are empowered to manage their disease and ongoing healthcare needs.
3. Patient outcomes and patient experiences are enhanced through a more coordinated, adaptive and responsive service system.
4. Patients can get timely and equitable access to services across the care continuum that is not constrained by geographic location, cultural or linguistic status, level of disability or other factors such as age, gender or socioeconomic status.

5. Of significance to this pathway is the removal of the siloed approach to the delivery of services to people at all stages of CKD, through improved planning and integration of care and treatment across the entire journey from diagnosis, to treatment interventions (transplantation, dialysis and RSC) through to end-of-life care. This pathway also emphasises closer engagement with other clinical disciplines as integral partners in care including, endocrinology, cardiology, primary care, palliative care and geriatrics.

The development of the RICP aligns with all relevant state and national policies. It draws on other clinical sectors’ approaches to service improvement and, in particular, cancer services and palliative care.

Audience
The RICP and the supporting web-based tool have been developed to be used by:

- clinicians involved in the provision of renal healthcare
- health service executives and managers with responsibilities for operating, planning and reviewing patient care services
- Department of Health and Human Services personnel involved in planning, managing and funding renal health services
- other professional organisations, including peak bodies, colleges and associations.

i Renal services typically have had ongoing relationships with vascular surgery and urology.
A better patient journey

Approximately 1.7 million Australians (1 in 10), aged 18 and over, have indicators of CKD such as reduced kidney function and/or albumin in the urine. Kidney and urinary tract diseases are the ninth leading cause of death in Australia, yet fewer than 10 per cent of people with CKD are aware they have this condition. CKD is a stronger risk factor than diabetes for future coronary events and all-cause mortality, and a person with CKD is 20 times more likely to die from a heart attack or stroke than progress to CKD Stage 5. CKD and its complications are reported to be more lethal than breast cancer, prostate cancer and road deaths.

Definition of an integrated care pathway

An integrated care pathway (ICP) is a multidisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes. Variations from the pathway may occur as clinical expertise is exercised to meet the needs of the individual patient.

ICPs are important because they help to reduce unnecessary variations in patient care and outcomes. They support the development of care partnerships and empower patients and their carers.

ICPs can also be used as a tool to incorporate local and national guidelines into everyday practice, manage clinical risk and meet the requirements of clinical governance (by ensuring that clinicians have access to the most up to date guidelines and tools).

The pathway also focuses on enhancing sustainability across the sector by developing models of care that provide clear and consistent approaches to the delivery of care and a shared understanding of service capability across the care continuum from disease prevention and early detection through to end-of-life care.

Chronic kidney disease in context

CKD is a progressive, irreversible disease that causes kidney function to deteriorate over several years, and is defined as abnormalities of kidney structure or function, present for more than three months, with implications for health.

The rate of disease progression can often be slowed through early detection and intervention and good clinical management of the disease, including addressing other contributing risk factors such as diabetes, cardiovascular disease (CVD) and hypertension.

Treatment strategies to slow progression and reduce cardiovascular risk include:

- enhanced lifestyle intervention and management ('prehabilitation')
- dietary advice and intervention
- medical management to control blood pressure and blood glucose, and reduce albuminuria.

In some patients, CKD will continue to progress, despite a proactive approach to intervention and management. Ongoing screening and assessment for associated complications and comorbidities are essential, and may include the monitoring of:

- malnutrition
- cardiovascular disease and dyslipidemia
- diabetes
- anaemia due to impaired erythropoiesis and low iron stores
- mineral and bone disorders
- depression and decreased cognitive and functional status.

Disease progression whereby residual kidney function is not adequate to sustain life, is the most severe form of CKD and is classified as CKD Stage 5. At this point, treatment options include:

- kidney transplantation
- maintenance dialysis
- renal supportive care (RSC).
Coordination, patient education and ongoing support are important components of quality CKD care, but the tertiary healthcare systems is created to provide acute and episodic care, rather than chronic care. The effectiveness of team-based chronic care management for people with CKD is well established but not widely implemented; there are also significant challenges in coordination of care between sectors and service providers.

Thus, the challenge lies in designing models of care and a service system that identify people with undetected CKD, define individual needs, provide interdisciplinary care and measure effectiveness to ensure that CKD detection, early intervention and treatment is accessible, equitable and sustainable.

A defining feature of this RICP is that it describes the pathway of care across the entire CKD continuum from early detection through to treatment and death, as well as including all treatment options.

**CKD Stage 5 versus end stage kidney disease/failure**

CKD Stage 5 is commonly referred to as end-stage kidney disease (ESKD) or end stage kidney failure (ESKF). It is of note that in the United States, end-stage renal disease is an administrative term used to indicate that a patient is treated with dialysis or transplantation, which is the condition for payment for healthcare by the Medicare ESRD program.

The classification of ESRD does not include patients with kidney failure who are not treated with dialysis and transplantation (for example, RSC). Thus, although the term ESRD provides a simple operational classification of patients according to treatment, it does not precisely define a specific level of kidney function, because this is determined by the level of kidney function.

The VRCN also is of the opinion that the term is not patient centred, because it carries a strong negative connotation which is often interpreted by patients and their families as nearing death. In contrast, CKD Stage 5 is a more neutral term that does not imply finality.

In Australia, the two terms are often used interchangeably in the literature, and therefore may also be used interchangeably in this document.

**Key stages of CKD**

Table 1 describes the key stages of CKD which are generally defined using a measure of estimated glomerular filtration rate (eGFR) with regards to:

- lead responsibility for patient care
- key signs and symptoms
- main aims and interventions.
Table 1: Key stages of CKD, intervention and management

<table>
<thead>
<tr>
<th>Stage</th>
<th>Primary prevention</th>
<th>Early detection</th>
<th>Secondary prevention</th>
<th>Specialist nephrology services</th>
<th>Treatment - transplantation, dialysis, supportive care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal kidney function</td>
<td>Kidney damage with normal GFR (&gt;90)</td>
<td>Kidney damage with mild reduction in GFR (60 - 89)</td>
<td>Moderate reduction in GFR (30 - 59)</td>
<td>Severe reduction in GFR (15 - 29)</td>
<td>Established Stage 5 CKD (GFR &lt; 15)</td>
</tr>
<tr>
<td>Stage 1</td>
<td>Stage 2</td>
<td>Stages 3a &amp; 3b</td>
<td>Stage 4</td>
<td>Stage 5</td>
<td></td>
</tr>
<tr>
<td>Responsibility</td>
<td>Population health</td>
<td>Primary care</td>
<td>Primary care plus specialist care if indicated</td>
<td>Specialist renal services (secondary or tertiary)</td>
<td>Specialist care plus tertiary hospital services</td>
</tr>
<tr>
<td>Aim</td>
<td>Reduce preventable causes of disease</td>
<td>Care of people at risk of developing, or who have CKD</td>
<td>Services for people with early, stable CKD</td>
<td>Services for people with advanced stage CKD</td>
<td>Services for people with Stage 5 CKD</td>
</tr>
<tr>
<td>Signs and symptoms</td>
<td>Typically asymptomatic</td>
<td>Often asymptomatic</td>
<td>Asymptomatic</td>
<td>Asymptomatic or mild symptoms</td>
<td>Range of symptoms</td>
</tr>
<tr>
<td></td>
<td>May have high blood pressure and possible dysfunction in other organs</td>
<td>May have high blood pressure and possible dysfunction in other organs</td>
<td>Dysfunction in other organs</td>
<td>Abnormalities in other organs</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increased creatinine and urea in the blood</td>
<td>High levels of creatinine and urea in the blood</td>
<td>Kidney function may no longer be adequate to sustain life</td>
<td></td>
</tr>
</tbody>
</table>

Early detection and risk reduction

Early detection and management

Pre-treatment education

Pre-emptive transplant

Preparation for transplant

Preparation for dialysis

Dialysis

Renal supportive care

Supportive approach to care (including assessment)
Key principles

To ensure consistency in approach and practice, across the CKD stages, five key principles underpin the RICP:

1. person-centred care and shared decision making
2. screening and assessment
3. information and education
4. integrated care
5. access and equity.

Person-centred care and shared decision making

Person-centred care (or patient-centred care) is healthcare that is respectful of, and responsive to, the preferences, needs and values of patients and consumers. Person-centred care is recognised as an essential dimension of high-quality healthcare, and there is strong evidence that a person-centred focus can lead to improvements in healthcare quality and outcomes by increasing safety and cost-effectiveness, as well as patient, family and staff satisfaction.

Person-centred care supports people to participate in decisions about their healthcare through collaboration, and focuses on collaboration between health workers, the person and their family and carers. Person-centred care is centred on the person and respects their wishes and needs. It is demonstrated by consultation with the person about their healthcare and their active participation in shared decision making.

Person-centred care:
- provides room for the person’s story through involvement in, and beyond, consultations
- stresses the importance that each individual is seen as a person
- pays attention for context as well as the symptoms or problems of that person, taking into account social, psychological and biomedical factors
- places emphasis on a dialogue between the person and healthcare provider
- explores emotional cues and shows empathy
- adjusts information and advice to the person’s context, and frames it in a positive way
- involves the person in the management of their illness
- recognises that the health professional is also a person

Shared decision making ‘is a consultation process where a clinician and patient jointly participate in making a healthcare decision, having discussed the options and their benefits and harms, and having considered the patient’s values, preferences and circumstances’.

Shared decision making recognises the importance of both patient preferences and evidence-based medical indications and supports the principles of person-centred care and patient empowerment. It is a process by which clinicians and patients work together to select treatment and management and will inform the patients care plan and advance care plan or directives as appropriate.

Screening and assessment

Screening is a method of determining the presence of a symptom or issue in a person or group of people with a high probability of having, or developing, such a concern.

These concerns may be related to:
- symptoms and side effects
- physical changes such as, reduced functional or mobility status, or impaired cognition
- psychological such as HRQoL, depression, anxiety or emotional issues
- social concerns such as HRQoL, financial issues and so on.

Screening may involve the use of a validated tool or may rely on patient self-reporting. It does not provide sufficient amounts of data to establish a diagnosis, but it can identify whether the person needs assessment, evaluation or further testing.
Assessment is a structured approach to review a specific issue or concern, such as pain, pruritus or anxiety which may have been identified by screening. It is a comprehensive and consistent way of identifying and subsequently meeting the person’s needs. Assessments may involve the use of a validated tool.

In addition to the achievement of quality outcomes for individual patients and their families, the development and use of a suite of standardised tools to be used for assessment with patients with CKD can provide data that enables benchmarking across services and the identification of areas for improvement.\(^\text{15}\)

Commencing in 2017, the Australian Commission on Safety and Quality in Health Care (ACSQHC) propose to introduce a new National Safety and Quality Health Service Standard (NSQHS), namely, Comprehensive Care (CC),\(^\text{16}\) with the aim of ensuring that consumers receive comprehensive care. This is expected to be achieved by using an ‘integrated screening, assessment and risk identification processes to develop care plans that are based on agreed goals of care’. The proposed actions required to achieve this standard include ‘systems in place for a formal assessment and screening process; use of agreed validated and/or best practice tools; documentation of findings of the screening and assessment and the development and documentation of an individualised care plan’.\(^\text{16}\)

In anticipation of this, the VRCN and renal services are collaborating on a project to develop a suite of agreed screening and assessment tools for Victorian renal services. Based on existing and validated tools, the aim is to facilitate improved patient care and enhanced benchmarking between service providers.

Information and education

Informed decision making by patients requires a good understanding of all suitable treatment choices, including the advantages and disadvantages of each option.

All patients presenting with CKD should have access to good-quality, evidence-based CKD education irrespective of cultural or linguistic barriers or the timing of presentation. This is requires understanding of the health literacy needs of patients and their families. Where needed, those with poor health literacy should be supported to improve understanding of their disease and the options available to them.

Integrated care

Integrated service delivery is ‘the organisation and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money’\(^\text{17}\)

Integrated care aims to create seamless, effective and efficient care that responds to every aspect of a person’s needs, across physical and mental health, in partnership with the individual, their carers and family.\(^\text{18}\)

People with CKD often have other comorbidities and several care providers. It is important that all care providers, along with the patient and their carers, work together towards the same health goals. The key to effective integrated care is good communication between all providers and a level of mutual trust regarding knowledge, skills and expertise.
Access and equity

Ensuring an accessible renal service system is important. It is also important that, with the support of health service providers, patients are able to easily navigate their way through and within the service system.

Underlying this principle is the goal of providing as much treatment and support as possible as close to the patient’s home, removing barriers to access, and the provision of clinical care that is consistent and predictable across the care continuum and between service providers.

Victorian renal services need to provide a level of care that is sensitive to the needs and requirements of patients from diverse backgrounds and responsive as far as practicable to the particular circumstances of individuals. To achieve this, all Victorians with CKD will have access to the best possible care and treatment irrespective of their cultural or linguistic background, geographic location, age or other factors.
A supportive approach to kidney disease

Underpinning the RICP and the key principles is a ‘supportive approach’ to patient care and disease management.

A supportive approach helps the patient and their family to understand and cope with their condition and its treatment. It enables the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. A supportive approach ensures that there is referral to those services, both generalist and specialist, that may be required by patients along the CKD journey from diagnosis to death. It also addresses a wide range of needs across the continuum of care and is a core component of evidence-based clinical care.

In the context of Victorian renal services, renal supportive care (RSC) is defined as a specific treatment choice for people with CKD Stage 5. It addresses the needs of those for whom dialysis and transplantation is not a preferred option, or for whom these treatments are not clinical suitable. RSC is sometimes referred to as ‘conservative care’, and may include palliative care as part of the treatment approach. RSC does not mean end-of-life care. End-of-life care is the final stage of care for all three treatment options.

Advance care planning

A key element of RSC is advance care planning (ACP), which is the process of planning for future care by making known a person’s values, beliefs and preferences so that they can guide clinical decision making at a future time when that person cannot make, or communicate their decisions, due to a lack of capacity. ACP allows people to clearly express their values and preferences to inform clinical decision making when they are too unwell to directly participate. The department’s Advance Care Planning Strategy 2014–2018 provides guidance for Victorian health services in the implementation of ACP.

Routine clinical care should provide opportunities to discuss and review people’s wishes and preferences at clearly identified points along their care journey. While the emphasis with ACP is on future care and preferences for future care for when the person cannot participate in decision making about that care, the ongoing ACP discussion can assist in defining the goals of current care and operationalising shared decision making.

Developing an ACP involves:

- having a conversation about what health decisions are important
- identifying who would make decisions if the person was unable to participate (in Victoria, an Enduring Power of Attorney Medical, who can decide whether to consent to medical or dental treatment, and can refuse medical treatment on their behalf or Enduring Power of Attorney for personal and/or financial matters)
- determining what those decisions would be.

ACP can be initiated at any time; however, there are several key trigger points during a person’s treatment and care that provide a good opportunity to discuss ACP including:

- when a person indicates they would like to talk about their future care and treatment
- key points in the person’s illness trajectory (such as after hospitalisation)
- a change in the patient’s condition or when they experience an unstable phase of their illness
- as a routine part of the care for key groups, such as those with chronic progressive disease, people approaching end of life, and people who are managing multiple comorbidities.

Renal services should include ongoing discussions around ACP as part of normal routine clinical practice.
Communication

It is the responsibility of the healthcare system and all people within its employ to ensure the communication needs of patients, carers and their families are met. Every person with CKD will have different communication needs, including cultural and language differences. Communication with patients should be:

- individualised
- truthful and transparent
- consistent
- in plain language (avoiding complex medical terms and jargon)
- culturally sensitive
- active, interactive and proactive
- ongoing
- delivered in an appropriate setting and context
- inclusive of patients and their families.

In communicating with patients, healthcare providers should:

- listen to patients and act on the information provided by them
- encourage expression of individual concerns, needs and emotional states
- tailor information to meet the needs of the patient, their carers and family
- use professionally trained interpreters when communicating with people from culturally and linguistically diverse backgrounds
- ensure patients, their carers and family have the opportunity to ask questions
- ensure that the patient is not the conduit of information between care providers (it is the provider’s and healthcare system’s responsibility to transfer information between health service providers)
- take responsibility for communication to the patient
- respond to questions in a way the patient understands
- enable all communication to be two-way.

Health literacy

Health literacy is about how people understand information about health and healthcare, and how they apply that information to their lives, use it to make decisions and act on it. Health literacy has been shown to be important, and there is strong and consistent evidence that links good health literacy with positive health outcomes and health behaviours in individuals. Understanding health and healthcare information is essential across our entire life course, but becomes critical for people with a chronic and complex disease.

Raising awareness, understanding and competence in health literacy for both patients and renal healthcare workers will ultimately improve outcomes for patients and assist health services and their staff to provide accessible, safe, and high quality care to their patients. Achieving this requires a coordinated and targeted approach to improving health literacy by embedding it into patient and workforce educational programs, as well as developing and implementing policies and strategies to support action specifically targeted at improving the health literacy of the people with CKDs.

Further information

- Department of Health and Human Services
  Advance Care Planning
- Advance Care Planning – have the conversation: A strategy for Victorian health services 2014–2018
- Advance Care Planning Australia
- Department of Health – Health Literacy Program
Fact: Consumer-focused design principles promote good interpersonal communication

‘Services should adopt the following design principles as the basis of improving health literacy by improving interpersonal communication. Good communication from a consumer or carer perspective is:

- being listened to
- being encouraged to ask questions
- communication without jargon
- being able to understand the health professional
- being understood culturally and linguistically
- having the information to know what to do, when, and not being bombarded with information (verbal and/or written) at one instance
- having health professionals check information needs as care progresses, taking into account health status and the needs of accompanying carers
- being provided with consistent messages
- being directed to reliable sources of additional information or support
- having health services and professionals communicate effectively with each other about the consumer, carer or family.’

Five Rs of renal disease

Another approach to supporting the management of CKD across the care continuum is the ‘Five Rs’ conceptual model. This model is outlined in more detail in Appendix B. The Five Rs conceptual model focuses attention on five keys areas: risk, recognition, response, renal support and rehabilitation. Adapted from the model developed by Lewington et al., the model provides an approach for focusing attention on the key factors that require attention and intervention across the disease trajectory. The five Rs model can be used to assist with the development of targeted education, workforce requirements and clinical care to ensure that inventions are appropriate, timely and undertaken by the right clinicians, whether they be physicians, nurses or allied health. The Five Rs model aligns with the key elements articulated in this pathway and throughout the steps of care.

Accessing external support services

People with CKD invariably have other health conditions and personal care needs besides those directly associated with their CKD. These health conditions and care needs may be precursors to the development of their CKD (such as diabetes or CVD), health conditions arising as a consequence of the CKD (such as some cancers, bone disease, malnutrition, or poor blood pressure control). In addition, within the CKD population there are those with mental health issues, disabilities of various types (for example, visual, acuity or physical), as well as cognitive impairment, drug and alcohol issues, or emotional, financial or relationship issues. Some people with CKD will also experience difficulties relating to maintaining employment or study, travel and transport, physical fitness, personal care or ability to self-manage.

Historically, patients referred to specialist renal services for their care and treatment have been predominantly managed by renal providers. However, in response to the recognition of the importance of providing more holistic care for patients with CKD, it is essential that renal services develop linkages and relationships with services outside the renal program to ensure that patients receive other specialist and expert care relevant to their needs.

A common barrier in accessing services is the perception that external services have a high level of hesitancy regarding the care of patients with CKD. Renal services need to work with other service providers to facilitate improved awareness and understanding of the CKD patient population to allay fears and misconceptions.
More recently, there has been a major emphasis on strengthening relationships between the Department of Health and Human Service’s Health Independence Program (HIP – refer to Attachment F for a list of HIP contacts), palliative care and renal services.

A comprehensive program of screening and assessment will help with the identification of other service needs, which may include:

- **Health Independence Programs** (HIP) – post-acute care (PAC), sub-acute ambulatory care services (SACS) and chronic disease management (CDM) programs
- specialist medical practitioners and programs (such as cardiology, diabetes, geriatrics, psychiatry, palliative care)
- case management services (such as Community aged Care packages, Linkages, Home and Community Care (HACC)
- care support services
- drug and alcohol services
- housing services
- financial advisory services
- work or educational support programs
- specialist programs and supports for Aboriginal and Torres Strait Islanders
- Aged Care Assessment Services (ACAS)
- paediatric services
- interpreter or other services for people from CALD backgrounds.

**Further information**
- Department of Health – Health Independence Program
- Department of Health – Sub-acute Services

## Prehabilitation and rehabilitation

Understanding and addressing the diverse needs of patients with CKD will facilitate improved HRQoL and overall wellbeing, which can impact health outcomes through a greater sense of personal engagement, motivation and self-management which will, in turn, impact health outcomes.

### Prehabilitation

The concept of ‘prehabilitation’ originated in sports medicine, and describes a program where athletes train intensively before a competition to prevent injuries.\(^{20}\) In a medical context, prehabilitation is employed with a view to prevent physical functional decline, with the greatest interest to date shown in the surgical setting.\(^{21}\) More recently, cancer prehabilitation has been conceptually expanded and described by Silver and Baima\(^{22}\) as a process on the continuum of care that occurs between diagnosis and the commencement of acute treatment.

Prehabilitation includes baseline physical and psychological assessments at functional level, identifies impairments and provides targeted interventions designed to optimise health to reduce the incidence and severity of current and future impairments. There is a growing body of scientific evidence that supports improved health outcomes and HRQoL, including decreased morbidity, improved physical and psychological health outcomes, increased range of potential treatment options, decreased hospital readmissions, and reduced direct and indirect healthcare costs.

This type of health promotion framework has not yet been described in the setting of CKD, but may well be worth exploring in combination with comprehensive assessment for people in CKD Stages 4 and 5 to support optimal preparation for living with advanced kidney failure and RRT, including their choice of treatment option.
Rehabilitation aims to maximise independence and HRQoL for people with a disabling medical condition, and maximise the likelihood that they will remain or become active and productive members of the community and minimise the long-term care needs and community support needs of these people. Rehabilitation is a coordinated program of medical treatment education, exercise, counselling and diet and is proactive and goal-orientated. It targets people with loss of function or ability. It aims to improve function and/or prevent deterioration of function and to bring about the highest possible level of independence, physically, psychologically, socially and economically. Physically active and emotionally supported patients are more likely to adhere to medication protocols and dietary regimes, and are less likely to require unplanned hospitalisation, thus not only enhancing their own health and wellbeing, but requiring less resources from their health service and the MDT.

Evidence from many studies suggests that structured education and exercise programs that commence prior to initiation of RRT can improve cardiorespiratory fitness, lower limb strength and HRQoL. Of all treatments, maintenance dialysis is invariably the most onerous, and is predicated on an assumption that patients accept and endure a burden of treatment that far exceeds that of any other chronic disease. Despite this, the level of psychosocial support for patients is minimal and variable across the state. Consequently, the opportunity to support patients to continue living a relatively normal life is lost and patients become acclimatised to an acute medical model of care (MoC).

People with diseases such as cancer, chronic heart disease or diabetes routinely receive rehabilitation and lifestyle support to enable them to remain active and achieve a high quality of life. While renal transplant recipients generally experience significant improvements in their health and HRQoL after transplant, the same is not typically the case for patients receiving dialysis. In contrast, the ability of patients receiving dialysis treatment to remain in employment or to continue with other social activities is influenced by factors such as a reliance on facility-based dialysis and compounded by lack of flexibility in treatment regimes. Consequently, patients must adapt their lives around a dialysis routine that is generally fixed and highly medicalised.

Bright idea: Should dialysis and transplantation be called ‘renal rehabilitation’?

Rehabilitation is a process that results in the restoration of an individual to his or her maximum possible level of function, ideally to the level of wellbeing prior to kidney failure. It includes emotional wellbeing and the capability to live well with dialysis. For people with kidney disease, this includes restoration of wellbeing, physical performance, emotional stability, social adjustment and work capacity.
While many patients will feel significantly better once established on dialysis than they have felt for some time prior, due to the removal of fluid and toxins from their body, studies have also shown that patient’s level of overall health can deteriorate significantly within weeks after commencing dialysis,24, 25 and that debilitation and disability is generally regarded as ‘normal’.

A proactive approach to rehabilitation that commences prior to the initiation of dialysis treatment (prehabilitation) and the period shortly after the patient has become established on their course of treatment may provide an opportunity to implement strategies to improve patient health outcomes through a rehabilitative approach to CKD management. This approach is defined as the ‘well patient chronic disease model’ and aims to optimise health outcomes for each individual patient.

Figure 1 shows the key dimensions of the well patient model of care whereby the patient’s emotional health and functional status are given equal consideration with necessary medical care and applies to all people with CKD regardless of the stage of their disease or the treatment chosen for their CKD Stage 5.

Medical intervention is seen as a means to minimising treatment burden and maximising HRQoL and life expectancy. Patients are supported through a combination of optimal clinical care and a program of rehabilitative care to enable them to live a ‘normal’ life for as long as possible.

Figure 2: The well patient chronic disease model of renal rehabilitation

The will to live
- Has knowledge and expertise
- Meaningful life experiences
- Engaged/connected
- Good QoL
- Cognitively aware/alert
- Good mental health
- Low emotional stress

Participating in restorative care
- Decreased disability
- Participates in work/study
- Physically active
- Good diet/nutrition
- Optimal functional status

Receives optimal medical care
- Minimisation of treatment burden
- Increased life expectancy
- Decreased infection/complications
- Good medication management
Further information

- Smart et al, Exercise & Sports Science Australia (ESSA) position statement on exercise and chronic kidney disease, 2013
- Chau et al, Rehabilitation of patients with end-stage renal disease, 2003
- Renal Resource Centre, NSW
- Life Options Rehabilitation Advisory Council, Building quality of life: a practical guide to renal rehabilitation, 1997
- HIP
- Prehabilitation – Expert Review: Prehabilitation and rehabilitation session

Consent

All patients considering medical treatment are required to provide informed consent for the procedure or intervention. Specific conditions in this consent must be based on the patient’s personal goals, beliefs and values and therefore may include quite specific inclusions or exclusions to future treatment.

Consent may be formal in the form of a signed consent form or a verbal agreement between the patient (or their carer) and the clinician(s).

Written consent for dialysis or transplantation should be obtained at the time the patient is accepted into the renal program and regularly reviewed, because it is likely that the patient may change the terms of their consent based on changes to their health status, or other personal circumstances.

To ensure consistency and transparency in care and to reduce variation in consenting practice, all Victorian renal services hubs should utilise an agreed consent form for both dialysis and transplantation.

In the case of transplantation or surgery for access creation for dialysis, it is expected that surgical consent would be obtained at the time of surgery.

Pathology

The VRCN and the Victorian Hub Reference Group (VHRG) have developed a state-wide routine pathology schedule (Appendix E) for people on facility-based maintenance haemodialysis (HD).

The aim of the schedule is to ensure that there is a clearly documented minimum standard for routine pathology testing in the satellite dialysis setting. This ensures that all patients, regardless of geographic location, have regular and clinically meaningful pathology review in the context of all assessment parameters for holistic care.

All renal services should adhere to the pathology schedule. Where clinically indicated, additional pathology testing may be required.

Organ donation

While this project does not explicitly address the issue of organ donation, it is acknowledged that it is critical to the success of the kidney transplantation program. In Victoria, several organisations, including the Australian Red Cross Blood Service and DonateLife Victoria, work alongside specialised health professionals and hospitals to implement the national Organ and Tissue Authority’s reform agenda, which funds a range of initiatives to fund and promote organ donation in Australian health services. Protocols have also been developed to ensure equitable and transparent transplant criteria.
In recent years, there have been several major developments in kidney organ donation that have had a positive impact on the availability of organs, including:

- the Australian paired kidney exchange program
- the greater acceptance of extended criteria kidneys
- improved understanding around immunosuppression and immunological leading to desensitisation protocols that enable transplant for ABO incompatible and highly sensitised patients.

The department will continue to work with transplant services to support the introduction of new technologies and other strategies that will improve access to organs for transplantation and enhance patient outcomes.

**Further information**

- Department of Health and Human Services [Organ and Tissue Donation Program](#)
- Australian Government’s [Organ and Tissue Authority](#)
Steps in care for people with chronic kidney disease

The steps in care for people with CKD outline the key milestones in the patient journey from early detection and diagnosis, through to treatment and ultimately end-of-life care. While the steps are presented as linear in this RICP, the reality is that, for many patients, their CKD journey will be anything but linear, especially as their disease progresses and they move between treatment options.

In addition, the nature of the disease means that many patients can influence their disease trajectory, especially the group whose kidney disease, is a consequence of modifiable lifestyle behaviours.

Five key steps of care are described (see Figure 3). Each step is described in more detail in the following chapters and the optimal care pathway for each step is defined. (refer also to Table 1).

**Goals of care**

- Greater community awareness of CKD & CKD risk factors.
- Systematic and targeted CKD screening.
- Routine and regular monitoring of populations at risk.
- Enhanced management of CKD to prevent or slow disease progression.

**Figure 3: Steps of CKD care**

**Step 1**
Early detection and management of people at risk

**Step 2**
Secondary prevention and management

**Step 3**
Preparation for treatment of CKD Stage 5

**Step 4**
Treatment
- Transplantation
- Dialysis
- Renal supportive care

**Step 5**
Management of end-of-life care

**CKD Stage 1**
Population health & primary prevention

**CKD Stage 2**
Early detection, risk reduction & lifestyle management

**CKD Stage 3a**
Risk minimisation & managing underlying causes of CKD

**CKD Stage 3b**
Managing complications & early treatment planning, including referral to a specialist renal service

**CKD Stages 4 & 5**
Comprehensive treatment planning and decision making, pre-emptive transplant, access creation, referral to external support services

**CKD Stage 5**
Treatment initiation and ongoing management of disease, including screening and assessment for HRQoL, cognitive and functional status and symptom management

**CKD Stage 5**
Planned and supported, high quality end-of-life care that minimises distress, discomfort & unnecessary symptom burden
Step 1: Early detection and management: CKD Stages 1 and 2

CKD Stages 1 and 2 focus on prevention, early detection and management of CKD, and are classified as:

1. Stage 1: eGFR ≥ 90 mL/min/1.73 m²
2. Stage 2: eGFR 60–89 mL/min/1.73 m².

- People are only classified as having Stage 1 or 2 CKD if there is also the presence of albuminuria, proteinuria or structural or pathological abnormality of the kidney.
- Because kidney function naturally deteriorates over time, many older people (> 75) will have Stage 1 or 2 CKD, but unless any of these other indicators are present, the person should not be diagnosed with CKD.

Identifying progressive CKD

- Obtain a minimum of three GFR estimations over a period of not less than 90 days.
- For patients with newly diagnosed reduced eGFR, repeat test within two weeks to exclude acute kidney injury (AKI).
- CKD progression is defined as a decline in eGFR of > 5 mL/min/1.73 m² within one year, or > 10 mL/min/1.73 m² within five years.

Prevention

Addressing the common risk factors for CKD such as diabetes, hypertension and cardiovascular disease will be important for reducing its incidence and the need for RRT in Victoria. The silent nature of the early stages of CKD presents challenges for monitoring the true impact of the disease because people may progress through to more serious stages without detection. An increase in early recognition of CKD in people at high risk is a national health priority and the setting that offers greatest opportunities for advancement is general practice. Australian research indicates that diagnosis of early CKD is suboptimal within general practice, with one recent study showing that only 18 per cent of people with abnormal kidney function were correctly identified as having CKD.

Early detection and risk factors

Australia does not have a population screening program for CKD, and the case for this remains under debate. Current evidence suggests that the optimal cost-effective strategy is targeted, opportunistic screening of patients with one or more risk factors for CKD. Early stages of kidney disease are often asymptomatic, are detected during the evaluation of comorbid conditions and may be reversible. While one in three Australians are at increased risk of developing CKD, only around one in 1,400 will require transplantation or dialysis treatment. Rapidly progressive diseases may lead to kidney failure within months, but most diseases evolve over decades, and some do not progress after many years of follow-up.

The shared risk factors and complex causal relationships between CVD, diabetes and CKD often result in multi-morbidity, more severe illness and poorer prognosis.

Further information

- Kidney Health Australia
- National Vascular Disease Prevention Alliance (NVDPA)
- Australian Chronic Disease Prevention Alliance, Networking Health Victoria
- Royal Australian College of General Practice (RACGP)
- Australian Practice Nurse Association (APNA)

Relevant guidelines include:

- KDI GO guidelines
- KHA-CARI Guidelines

Patient concerns

The general lack of public awareness regarding the functions of healthy kidneys and what happens when kidney function deteriorates means that many people lack knowledge about CKD risk factors and the potential impact of kidney disease.
Strategies to enhance person-centred care for patients at risk of CKD or those with early diagnosed CKD

- Help patients understand the cause of the disease.
- Explore the underlying issues and barriers to change that the patient may be facing.
- Assist patients with well-defined and clear approaches to improving their health and wellbeing.
- Identify areas of resistance or non-adherence to implementing health improvement strategies.
- Provide ongoing support based on clear and open communication.

Because people with early stages of CKD are typically asymptomatic, a non-related visit to the GP or other specialist may result in an unexpected conversation about kidney problems and, despite a sensitive approach by the attending physician, early responses to such news may include shock, disbelief and denial.

Making kidney checks for at-risk populations routine will create greater awareness of kidney health in the broader population, facilitate improved understanding of the potential impact of kidney disease if left untreated and enable patients time to address the cause of their disease.

Effective prevention will enhance the patient’s HRQoL, prevent or reduce complications and improve health outcomes – both at the patient and population health level.

Evidence suggests that many other factors (such as health literacy, income, cultural values and access to services) determine how clinical care, including preventive care, is provided to and accepted by patients. Patients may require the confidence to discuss their concerns with their GP, as well as ongoing support to achieve change, especially if the intervention(s) are likely to take a long time or are ongoing (such as smoking cessation, diet and exercise and so on).

Further information
- Australian Institute of Health and Welfare, Population Health FAQ
- Australian Department of Health and Ageing, Primary healthcare reform in Australia: Report to Support Australia’s First National Primary Health Care Strategy.
- Royal Australian College of General Practitioners, Putting prevention into practice: guidelines for the implementation of prevention in the general practice setting (2nd edition), 2006

Person-centred care and shared decision making

Patients at risk or with early stage CKD will benefit from a proactive approach to detection and intervention strategies through better management of their disease.

Source: Patient interviews 53

“Can you fix my kidney problems?”

“I didn’t even know I was at risk of kidney disease until it was too late”

“I wish I’d been told sooner about the importance of looking after my health and kidneys”
Screening and assessment

Early detection of CKD relies on the capacity of health professionals in the primary care setting to understand and recognise risk factors and to act effectively when the risks are identified. This requires underpinning knowledge and well-designed systems and tools that meet the challenges of general practice, both now and into an era of increasing service demand.

Screening and assessment should include:

- assessment of all people attending their GP for CKD risk factors such as diabetes, hypertension, smoking and so on, as part of routine primary health encounters.
- targeted annual screening of people at risk of CKD (urinary ACR, eGFR and blood pressure).
- ongoing assessment of patients diagnosed with early CKD should include:
  - absolute cardiovascular risk assessment using the Australian CV Tool
  - Chronic Disease Management (CDM) Risk Assessment at least every 12 months (more frequently for patients with rapid decline in kidney function or other changes in health status).

Information and education

In this early stage of CKD, specialist referral and intervention is often not required, and the patient can be adequately managed by their general practitioner (GP) and other primary healthcare workers. However, CKD is a complex disease, and it is therefore important that the primary healthcare workers are able to easily access up-to-date education and resources to enable them to confidently manage patients with early CKD. Both the Royal Australian College of General Practitioners and KKA have both developed resources targeted at GPs. Web-based decision-support tools are also currently under development.

Fact: People with the following risk factors need to be routinely screened for CKD:

- obesity
- hypertension
- diabetes mellitus
- cigarette smoking
- established cardiovascular disease
- age > 60
- Aboriginal and Torres Strait Islander peoples; Maori and Pacific peoples
- family history of Stage 5 CKD or hereditary kidney disease in a first- or second-degree relative
- severe socioeconomic disadvantage
- a history of acute kidney injury (AKI).

Further information

- CKD Management in General Practice
- Health Independence Program (which includes HARP)
- Australian Absolute Cardiovascular Disease Risk Assessment and Risk Calculator
Strategies to educate and inform people at risk of developing CKD include:

- developing simple community messages to improve health literacy and awareness
- providing clear and consistent messages based on CKD and chronic disease management (CDM) guidelines and current evidence in all education approaches is essential for effective management, optimal outcomes and consumer confidence. For individuals with diagnosed early CKD, information and education should include:
  - baseline information about kidneys and kidney disease
  - tailored information about reducing risk factors and management of underlying disease
  - emphasis on importance of follow-up health checks and monitoring
  - focus on motivational learning strategies to promote engagement, positive self-management and lifestyle changes to reduce CKD risk/progression
  - genetic counselling for people with inherited CKD (consult with nephrologist re timing due to potentially protracted clinical course of CKD).

**Integrated care**

Most patients with early CKD can be successfully managed through primary care in collaboration with other community-based healthcare providers. Increasingly, general practice nurses (GP nurse) are taking a greater role in the management of patient screening programs, and have the capacity to work with their patient population in managing risk reduction and disease prevention.

Currently, there is little patient level information regarding early stage CKD, and a register that routinely collects information and outcomes (details to be determined) on all patients diagnosed with CKD, commencing at CKD Stage 1 would potentially provide significant benefits to future patient care.

**Further information**

- Chronic Kidney Disease Management in General Practice
- Guidelines for preventive activities in general practice – RACGP Green Book
- Putting prevention into practice: guidelines for the implementation of prevention in the general practice setting – RACGP Red Book

Other complementary approaches that add value for the GP include:

- the KHA QKidney®risk calculator
- learning activities that attract continuing professional development (CPD) credits for GPs and general practice nurses (GPN), such as KCAT modules.

---

**Fact: Lifestyle modification – CKD Stages 1 and 2**

- No restrictions on dietary protein or phosphate.
- Low salt diet recommended to help control blood pressure and reduce the risk of CVD.
- Implement smoking cessation support.
- People with a waist circumference of ≥ 94 cm for men and ≥ 80 cm for women to be referred for weight management and dietetics support.
- Regular exercise to be encouraged.
- QoL and psychosocial stress to be routinely assessed and actively managed.
- People with issues relating to activities of daily living to be referred to an occupational therapist.
Access and equity

Compared to their metropolitan counterparts, Australians living in remote and very remote areas typically experience higher rates of CKD, increased hospitalisation rates and greater CKD related mortality. Some demographic groups have higher rates of death from chronic diseases, particularly Aboriginal and Torres Strait Islander people, those in the lowest socioeconomic groups and those living in remote areas of Australia. Renal services should actively address disparities in access for patients of Aboriginal and Torres Strait Islander or CALD backgrounds and provide information and services that are sensitive to people’s cultural and linguistic status.

Prevention and management of CKD requires the provision of effective primary healthcare services, including education support. Targeted screening activities should be broadened to include places such as the workplace, community centres, pharmacies and so on.

Further information

- CKD Management in General Practice
- KDIGO Guidelines
- KHA-CARI guidelines for early chronic kidney disease

Suggestions for implementation

To improve the outcomes for people at risk of developing CKD or with diagnosed early CKD GPs and renal health services should:

- develop referral pathways to local services, especially for screening and assessment (for example, local pathology, pharmacy, radiology and so on)
- explore opportunities to link with other chronic disease management (CDM) programs (particularly diabetes and cardiac programs), especially in rural areas where there may be fewer local resources
- actively promote channels of communication and referral pathways between primary care and nephrologist to address areas of uncertainty with regard to CKD management
- collaborate with KHA in developing and disseminating community messages regarding kidney disease
- explore opportunities to assist with the education and up-skilling of GPs, primary care practice nurses and other community health staff.
Step 2: Secondary prevention and management of progressive kidney disease: CKD Stages 3a and 3b

CKD Stage 3, secondary prevention and management of CKD, has been subdivided as follows:

1. CKD Stage 3a: eGFR 45–59 mL/min/1.73 m²; secondary prevention – early stable CKD
2. CKD Stage 3b: eGFR 30–44 mL/min/1.73 m²; secondary management – established CKD.

Secondary prevention and management of CKD considers two cohorts:

1. People diagnosed with Stage 3a who are generally stable, where care is primarily aimed at maintaining or improving current health indicators, minimising risk factors, managing the underlying cause(s) of CKD and preventing or delaying progression of CKD and CVD.
2. People diagnosed with Stage 3b who have established CKD with additional care relating to the identification and management of complications and a determination of the risks and benefits of treatment options, including RRT, for those people who are likely to progress to Stage 5 kidney disease.

By CKD Stage 3, some patients may be experiencing several complications, including: anaemia, high blood pressure, along with changes in urinary function and sleeping patterns.

For patients diagnosed with CKD Stage 3a, patient care should largely be driven by primary care in cooperation and consultation with other relevant specialists and service providers, and be grounded in the patient’s holistic needs, values and life priorities.

For patients diagnosed with CKD Stage 3b, patients should have access to efficient and convenient specialist renal services, which may include a private nephrologist or public renal speciality service.

On average, kidney function declines with age at a rate of approximately 8 mL/min/1.73 m² per decade, although individual patients with CKD may have considerably greater decline in kidney function depending on their ability to self-manage their disease, other comorbidities and cause of disease. Many patients could potentially face significant kidney impairment within a short to medium term, creating a sense of urgency to ensure that CKD management is focused on individual patient needs and a clear understanding of the potential prognosis.

Managing progressive CKD

Patients may, by this stage, be experiencing several other issues that require more intensive intervention, including:

- depression, anxiety or other mental health issues
- comorbid disease
- sexual health problems (including pregnancy advice)
- socioeconomic issues
- disability.

Goals of care

✓ Slow or slow CKD progression.
✓ Optimise patient health-related QoL by addressing poor lifestyle behaviours and comorbidities.
✓ Optimal management of complications.
✓ Timely referral to specialist renal care.
Referral

- It is important that patients are referred to specialist nephrology services in a timely manner to ensure that they receive appropriate kidney care.
- Timing of referral should consider factors such as the person's age, health status, comorbid diseases, or rate of disease progression and be informed by evidence-based clinical guidelines.
- Ideally, patients will be referred to a renal specialist at Stage 3b or early Stage 4, depending on individual patient history, or if the risk of kidney failure within one year is 10–20 per cent or higher.
- Late referrals (less than three months prior to the need to commence dialysis) are often associated with increased mortality and hospitalisation rates, which in turn are linked with greater comorbidity, use of dialysis catheters and lower rates of transplantation. Continued effort should be made to reduce the rate of late referrals.
- The referral should include all relevant patient information, including:
  - detailed medical or family history
  - all relevant test results (pathology, radiology and so on)
  - assessments undertaken (for example, mental health, functional status and so on)
  - current medications or allergies
  - whether an interpreter or other support services are required.

Patient concerns

People with early, stable CKD are likely to experience a continued sense of denial, particularly if they are asymptomatic, of young age with a poor medium- to long-term prognosis, or of Indigenous identification. Such a lack of engagement can lead to low prioritisation of self-management in relation to risk reduction and treatment adherence.

People may ask, ‘Why should I worry about kidney disease when I still feel well?’ This may reflect complex barriers to acceptance of current and future impacts of CKD, such as psychosocial, cultural and health literacy issues.

In addition to the interventions identified for people with Stages 1 or 2 CKD, the objectives for the treating primary care clinician and specialist renal service (if required) are to:

- reduce risks of AKI including: nephrotoxic medications or volume depletion
- prevent/minimise complications of CKD
- continue to optimise health and quality of life
- refer to or consult with a nephrologist if indicated.

Source: Patient interviews
Person-centred care and shared decision making

Supporting patients to manage their CKD is achieved through a collaborative approach between the patient, their family/carer and the clinical team to:

- build self-confidence
- increase knowledge of their condition
- promote proactive and realistic goal setting
- address barriers to making lifestyle changes
- identify and addressing the patient’s psychosocial needs
- develop an agreed shared care plan with goals, actions and potential outcomes.

Fact: Characteristics associated with progressive CKD likely to lead to kidney failure:

- young age
- consistent decline in renal function over time
- presence of albuminuria
- underlying primary renal disease (such as primary glomerular diseases, diabetic nephropathy, or renovascular disease)
- high blood pressure
- development of CKD complications (such as increased serum phosphate and/or decline in haemoglobin levels).
Screening and assessment

Ideally, people with CKD will have been identified and effectively managed by their GP until such time that their kidney function is reduced to a level where specialist advice and intervention is required.

Regular and routine assessments by the patient’s GP should be undertaken as per clinical guidelines.

Nutritional status typically deteriorates as renal disease progresses. While malnutrition is common in CKD Stages 4–5, studies suggested that it can occur as early as Stage 3. Therefore, close monitoring of nutritional status, including protein and energy intakes, is recommended.1

Frequency of testing

- Review should be undertaken:
  - six- to 12-monthly for patients at Stage 3a
  - three- to six-monthly for patients at Stage 3b.

Further information

- KHA (2015) CKD Management in General Practice (3rd ed.)
- KDIGO Guidelines
- KHA-CARI guidelines for referral

Education and information

Patients require access to education in a timely manner to assist them to plan for such things as work, financial requirements, family arrangements, housing and so on, should their CKD begin to have a major impact on their health and HRQoL.

Education should include information as described in Appendix D: Elements of a successful education program, as well specific information about:

- changing modifiable lifestyle behaviours to reduce the rate of CKD progression
- prognosis
- the broad future treatment options should the disease progress to CKD Stage 5.

Education and information may be provided by the patient’s GP, or referred to a formal group education programs run by specialist renal services if deemed appropriate.

Patients should be offered information about peer support organisations such as Kidney Health Australia (KHA), the Dialysis and Transplant Association (DATA), Renal Resources Centre (RRC) for further information and support.

Information should focus on:

- maintaining a healthy lifestyle
- nutrition
- medication management
- risks associated with CKD
- importance of routine testing of kidney function
- future treatment options or other specific issues relevant to the individual patient. Where appropriate, patients may be provided with high level information about CKD Stage 5 and treatment options.
Integrated care

Because kidney function declines and as complications and comorbidities increase, the contribution of others will likely be needed to achieve optimal care. These may include the patient's significant others, GP nurse, nephrologist, advanced practice renal nurse/nurse practitioner, pharmacist, endocrinologist and/or other professionals specialising in diabetes, cardiologist, dietitian, vascular and transplant surgeons, mental health professionals, community health professionals, social worker, Aboriginal health worker.

To achieve good quality integrated care, it is recommended that:

- ongoing care is primarily managed by the patient's GP, with support from a nephrologist or renal service if required
- people with complex needs are supported by quality care coordination provided by appropriately skilled staff
- clinicians work collaboratively to exchange information necessary to provide high-quality care
- shared-care protocols are used by GPs and other specialist service providers to facilitate safe and appropriate shared care
- all patients have access to a mental health plan should they need one, typically overseen and monitored by their GP.

Fact: Lifestyle modification – CKD Stages 3a and 3b

- In addition to the lifestyle modifications identified for patients with Stages 1 and 2:
  - dietary management of hyperkalaemia
  - control blood pressure
  - good anaemia management – maintain haemoglobin between 100 g/L and 120 g/L
  - monitor nutritional status for signs of malnutrition
  - monitor and manage renal bone disease – routinely measure serum calcium, phosphate, alkaline phosphate and parathyroid hormone.

Bright idea: Telephone-based health education and coaching and tele-monitoring

**Telephone-based health coaching** provides an enhanced opportunity for targeted CKD management. Building on the agreed care plan, tele-coaching can:

- reinforce and support the shared-care plan
- assist in behaviour modification for example, smoking cessation, healthy eating, weight control, exercise and so on
- enhance medication management
- facilitate early identification of issues and risks.

**Tele-monitoring** can be used to collect ongoing ‘real-time’ clinical information on:

- blood pressure
- weight
- blood glucose levels.

To provide

**Fact: Lifestyle modification – CKD Stages 3a and 3b**

- In addition to the lifestyle modifications identified for patients with Stages 1 and 2:
  - dietary management of hyperkalaemia
  - control blood pressure
  - good anaemia management – maintain haemoglobin between 100 g/L and 120 g/L
  - monitor nutritional status for signs of malnutrition
  - monitor and manage renal bone disease – routinely measure serum calcium, phosphate, alkaline phosphate and parathyroid hormone.
Access and equity

Patients living in rural and regional areas should be able to receive access to ongoing management of their CKD as close to home as possible. To overcome disparity in access and equity associated with available services, health service providers should also consider alternative models of care such as outreach services, telehealth or decentralisation of services. Further consideration should be given to a case management model to provide enhanced coordination of care so that services delivery can be planned and streamlined.

If a patient has been referred to a specialist nephrologist, it may be possible for that patient to receive their ongoing management by their referring GP rather than the specialist. It is recommended that, in this scenario, there are well-understood criteria for re-referral back to the specialist. This option may be particularly beneficial where access to specialist renal services may be limited.

Suggestions for implementation

• Development of links with local GPs.
• Increased education of GPs and private nephrologists around effective and timely referrals.
• Patients with deteriorating kidney function are referred to specialist renal services in a timely manner.
• Patients are able to access a program of prehabilitation with proactive interventions and supports to facilitate maintenance of a healthy lifestyle or lifestyle modification.
• Patients are able access multidisciplinary care and support including medical, nursing and allied health.
• Patients are able to access information and education that is:
  – appropriate to the stage of their disease pathway
  – delivered in a format that takes account of cognitive or sensory impairment, disability, mental health issues or mental distress (for example, high anxiety), language or any other particular circumstances which may affect comprehension and understanding, including level of health literacy.
CKD Stages 4 and 5 are associated with severely reduced kidney function, and generally require specialist nephrology care. CKD Stage 5 is associated with the potential for kidney failure where kidney function may be insufficient to sustain life.

- CKD Stage 4: eGFR 15–29 mL/min/1.73 m²
- CKD Stage 5: eGFR < 15 mL/min/1.73 m²

**Treatment options**

For people with CKD Stage 5 there are three treatment options:

1. transplantation
2. dialysis
3. renal supportive care.

Patients should be provided with adequate information regarding each treatment option including the advantages, disadvantages, risks and benefits of each option and the likely prognosis.

**Referral**

All patients should be referred to a specialist nephrologist or nephrology service by early Stage 4 (eGFR of < 30 mL/min/1.73 m²), or at least twelve months prior to anticipated CKD Stage 5.

Patients considering transplantation should be referred to a specialist renal unit at least 12 months prior to the anticipated need for transplant, especially if considering a pre-emptive transplant. Rural renal units should be doing the majority of renal transplant workups, and referral to transplanting units could occur closer to the time of transplantation provided good communication processes have been established.

Patients choosing haemodialysis (HD) require timely referral to a vascular surgeon for the creation of their vascular access. This should be a minimum of three months prior to the commencement of dialysis to allow for maturation of the fistula.

Patients who present with CKD and likely need dialysis or transplantation within three months (that is, late referral), should have access to an accelerated pathway of education and access creation.

---

**ii** While the prognosis for people with CKD Stage 5 generally suggests a short survival period, it should be noted that there are also many instances of people surviving for months or years without RRT.
Some people approaching CKD Stage 5 will be clinically unsuitable for transplantation or dialysis. This is generally due to functional decline, frailty or coexisting serious medical conditions which make successful transplantation or dialysis therapy very unlikely. In some instances, the patient may have other reasons for opting to not commence dialysis (assuming unsuitability for transplantation). In these circumstances, renal supportive care (RSC) is the best treatment option for the patient.

Those choosing RSC should receive timely referral to a palliative care or other appropriate service (if required) in order to manage pain and other symptoms of kidney failure, as well as to provide additional support. The timing of this referral will depend on the individual needs of the patient and their family.

Fact: Late referrals can result in poor outcomes for patients

Late referral (defined as initiation of dialysis <1–6 months –usually <3 months – after initial referral to a nephrologist) of patients with CKD is associated with:

- increased patient morbidity and mortality
- increased use of temporary venous catheters at initiation of haemodialysis
- less use of peritoneal dialysis
- reduced likelihood of listing on a transplant waiting list and of transplantation
- increased need for and duration of hospital admission
- increased initial costs of care following the commencement of dialysis.\(^72\)

Fact: Patients presenting late can still receive optimal clinical care and treatment

- Planning for unplanned presentations through the development of an urgent start clinical pathway will mean that patients can still receive appropriate initiation of dialysis, including, in some case, haemodialysis with vascular access.
- Patients suitable for transplantation should be fast-tracked for work-up for Australian Organ Matching Service (AOMS) registration or a living donor transplant.
Patient concerns

Ideally, people who are approaching CKD Stage 5 will be well managed and well informed in advance of what to expect in the referral to a nephrology specialist service. Prior discussions with the referring clinician (GP or other specialist) provides an opportunity to address issues which are important to the individual’s HRQoL and adaptation to CKD Stage 5 care to be documented.

The wide spectrum of individual circumstances and experiences that precede referral to a renal specialist service means that patient concerns will vary significantly. In part, this will relate to how much knowledge they have acquired regarding their CKD, but many other factors will influence their preparedness for CKD Stage 5, such as family history of CKD, GP knowledge, health literacy, CALD status and age.

Person-centred care and shared decision making (SDM)

Person-centred care and SDM means that the information will be individualised for each patient, and therefore delivered in a manner that is clear and comprehensible to the patient’s level of health literacy, language skills and information requirements. To this end, patients may require interpreters or written, verbal or pictorial (for example, video) information of varying detail. The provision of links for people newly referred for CKD Stage 5 preparation to those who are established on a treatment has been highlighted, particularly by consumers, as a positive but underutilised method of informing decisions, adaptation to life changes and motivation.

To achieve good person-centred care and true shared decision making, clear and responsive communication channels should be established by each renal service to facilitate a nephrology consultation conduit for GPs and other specialists to support professional discussions regarding individual patients, negotiations regarding shared care and timely referrals.

Screening and assessment

All patients approaching CKD Stage 5 will have:

- early assessment for dialysis or transplantation without preconceived views as to patient suitability or preferences to any particular treatment or modality
- comorbid diseases reviewed and issues addressed
- ACP initiated (if not already discussed), otherwise reviewed and updated.
- relevant vaccinations and malignancy testing completed before transplantation or dialysis start
- periodic, planned reassessment of decisions is enabled, where individuals have dedicated time, adequate preparation and an appropriate environment in which to have such discussions.
In addition, all patients should undergo regular screening and assessment and treatment accordingly, including:

- performance/functional status
- physical symptoms
- depression/mental health
- cognition
- quality of life
- carer burden
- psychosocial issues.

The VRCN, in collaboration with the renal sector, is currently undertaking a project that aims to identify a process for comprehensive patient assessment for Victorians with Stages 4 and 5 CKD. The final outcome of this project is expected to be available by early 2017.

Transplantation

All people who are considering transplantation should have their suitability for kidney transplantation assessed at the earliest opportunity; preferably when patient has an eGFR of approximately 20 mL/min/1.73 m², or as appropriate, depending on rate of decline. Ideally, people will be offered a pre-emptive kidney transplant, if they are medically suitable and a suitable living donor is available.

Preparation for possible transplant should include:

- early identification and management of psychosocial or other lifestyle issues
- early referral of obese (BMI 735) to a Bariatric service where appropriate, noting that the time from first referral to target weight may be up to two years
- organ procurement – early identification of all potential donors and timely assessment of donor suitability, including surgical, psychological assessment and lifestyle modification if required
- living donor work-up to be undertaken in parallel with recipient assessment and work-up
- early consideration of combined kidney/pancreas transplant in suitable patients with Type 1 diabetes
- commencement of transplant work-up investigations which may include:
  - blood tests, infection screen, urinalysis
  - diagnostic procedures including cardiac work-up if necessary, noting that all candidates with diabetes or hypertensive renal disease should undergo thorough cardiac evaluation
  - immunological evaluation and pre-transplant desensitising if required
  - pre-transplant surgical interventions if necessary (for example, native kidney nephrectomy, cholecystectomy).

Key questions for patients considering transplantation

- Is the recipient physically and psychologically fit for a transplant?
- Are they likely to survive with a reasonable outcome (QoL, survival prognosis and so on)?
- Does the potential recipient understand the risks, benefits, side effects and commitment, including lifelong immunosuppressant regime?
- Is a living donor available? If not, are they prepared to commence dialysis while waiting for a deceased donor kidney?
- Has the patient and transplant team discussed recipient expectations – will they accept a marginal kidney or prefer to wait for a good match?
- Can the potential recipient maintain physical and psychological readiness for a transplant?
- Does the patient have an advance care plan?
**Dialysis**

Preparation for dialysis should begin about nine to 12 months prior to anticipated need (noting that rate of progression may vary for individuals and can be sometimes difficult to accurately predict). Vascular access should be created in patients with an eGFR 15–20 mL/min/1.73 m$^2$, in whom progression to CKD Stage 5 seems likely. Ideally, all patients should commence their treatment with a functioning, permanent access. Many patients may require HD at some stage of their disease; therefore, preservation of veins is a critical aspect of treatment planning for all patients and efforts should be made to limit phlebotomy and intravenous catheters to veins in the hand as well as cannulation of veins above the wrist in either upper extremity.

For those considering dialysis treatment they should:

- be assessed for their suitability for home dialysis as a first option
- understand the importance of timely access placement and the potential issues in delaying surgery
- receive additional support from other services if required
- have any acute or chronic complications of uraemia treated as per clinical guidelines.

---

**Key questions for patients considering dialysis**

- Has the patient received comprehensive education regarding dialysis options?
- Is the patient a candidate for PD?
- If not, is the patient a candidate for HHD or facility-based self-care dialysis?
- Has the patient received an assessment for vascular access?
- Is the patient hoping to receive a future kidney transplant?
- Is the MDT fully aware of the patient’s goals, expectations, concerns and values?
- Does the patient have an advance care plan?

---

**Renal supportive care (RSC)**

For those considering RSC, they will:

- understand that they will be fully supported by their renal MDT in the management of their CKD Stage 5
- understand that they can ‘change their mind’ and commence dialysis at any point in time (subject to clinical suitability)
- receive additional support from palliative care and other services if required.

---

**Further information**

- KDIGO Guidelines
- KHA-CARI Guidelines for CKD
Information and education

• At this stage, all patients should have access to a formal education program that includes discussions regarding the potential impacts of each option on their health outcomes as well as HRQoL. Fundamental to good patient education are the concepts and principles of health literacy.
• Renal services should be proactively identifying and addressing barriers to patients attending education programs. This may require greater flexibility in the way that education programs are delivered, including the timing of when an education program is offered, where it is provided, and how it is provided.
• Education and information provided to patients should be individualised and consistent with each patient’s level of health literacy, level of prior knowledge and cognitive status.
• Patients should be offered access to formal education programs which include comprehensive and unbiased information regarding treatment choices and location of treatment, including:
  − information regarding the advantages and disadvantages of each treatment option, including potential complications or side effects that may occur as a result of treatment or medication
  − the likely trajectory of their disease, including a reasonable estimate of prognosis
  − information about how they will be cared for at the end of life (no matter which treatment option they choose) and the choices they have at the end of life in respect to place of death and who will care for them.
• Patients should also have a good understanding of the commitment required for each of the treatment options. This may be: adherence to medication or treatment regimes, or self-care requirements, diet, fluid intake and smoking cessation. This commitment includes an understanding of the importance of timely decision making and the potential negative impacts in delaying referral to a specialist renal service or making a treatment choice.
• Patients will vary in the level of information that they require, with some preferring the clinical team make their decisions for them, while others will be highly engaged and self-motivated ensuring that they have accessed all available information to inform their decisions.
• It is important to identify and, where possible, address barriers to learning and motivation, such as cognitive impairment, disability (particularly hearing and vision impairment), denial, cultural beliefs, psychosocial stressors (for example, family issues, financial difficulties, transport issues and so on) or any other issues. Proposed strategies to address these issues include a more systematised and standardised approach to information and education using an agreed syllabus and adult learning principles.

Table 2 provides a summary of the key elements of a successful CKD education program that can then be adapted to meet the specifics of the broader patient population as well as individual patient needs.

Key questions for patients considering renal supportive care

• Has the patient and MDT discussed recipient expectations, personal goals, values and likely prognosis?
• Has the patient been referred to palliative care or other support or community services? Do they need to be?
• Is the patient’s GP aware of their condition and engaged as part of the ongoing care team?
• Is the patient a potentially suitable candidate for transplantation or dialysis? If so, have these options been fully discussed with the patient?
• Does the patient understand the risks, benefits and likely outcome of a non-dialytic option?
• Does the patient have the potential to be an organ/tissue donor (if clinically suitable), and has this been discussed with them?
• Does the patient have an ACP?
### Table 2: Key elements of a successful CKD education program

<table>
<thead>
<tr>
<th>Key elements</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Commencement</td>
<td>Commence early in the course of the patient's CKD pathway (eGFR less than 30 mL/min/1.73 m²), or whose kidneys are likely to fail within 12 months. Also involve late referrals including those who have recently started dialysis with no prior nephrology care</td>
</tr>
<tr>
<td>Program leader</td>
<td>Appropriately skilled CKD nurse educator, supported by a dietician and social worker and other members of the MDT as required</td>
</tr>
<tr>
<td>Target audience</td>
<td>Patients and their families/carers</td>
</tr>
<tr>
<td>Setting/format</td>
<td>One–on–one or in a group setting. Consider telehealth for patients unable to attend in person.</td>
</tr>
</tbody>
</table>
| Content            | Comprehensive written and verbal discussion of CKD including:  
|                    | • slowing or reversing loss of kidney function  
|                    | • importance of preserving veins for future dialysis access  
|                    | • kidney transplantation, including living and deceased donor options  
|                    | • dialysis treatment options, including PD and HD, home dialysis  
|                    | • RSC and what that means in the context of no other RRTs  
|                    | • impact of the treatments on lifestyle, prognosis, QoL, etc.  
|                    | • importance of advance care planning  
|                    | • end-of-life care.                                                                                                              |
| Frequency          | Should be ongoing, but ramped up at key decision milestones such as: prior to dialysis or transplantation or changes in clinical or psychosocial circumstances. Ideally patients will receive between three and six formal education sessions relevant to assist with choice of treatment as this will help avoid information overload and allow time to patients and their families to consider the information they have received and to come back with questions regarding that information. Patients changing treatment streams should receive further education. |
| Other resources     | Involvement of current patients including transplant recipients, those on dialysis (both home and centre-based) and, if possible, patients on a RSC pathway is encouraged. Tours of dialysis facilities for patients considering satellite dialysis. Advice regarding how to access good quality online resources, encourage linkages with consumer and peer support organisations. |
| Decision support   | Help patients to consider the treatment option that best suits their lifestyle, beliefs and values and is likely to provide the best QoL for themselves and their family. |

### Further information
- KHA Decision Aid
- Nephrology Educators Network (sub-group of the Renal Society of Australasia)
**Integrated care**

- Managing each individual’s care, the MDT should meet regularly to discuss treatment planning with each patient, with attention focused on medical and psychosocial impacts. Ideally, all patients will be discussed by the MDT prior to the patient making decisions about their treatment. Subsequent discussions by the MDT should also be held just prior to commencement of treatment to review and address any changes in clinical or personal status that might impact on treatment outcomes.
- Transplant recipients who are re-entering the CKD pathway as a consequence of a failed or failing transplant, should be reviewed irrespective of whether they have been discussed previously (for example, prior to transplant).
- All relevant results of any tests and assessments that have been undertaken should be available at the MDT meeting.
- Ideally, all patients (but particularly those with complex care needs) will be allocated a care coordinator, who will also be present at the MDT meeting.
- To ensure good integrated care:
  - patients should be informed of the membership of their MDT
  - patients should be provided with the details of a nominated care coordinator who is directly accessible to them and their family/carer(s)
  - the patient’s GP should be notified of any critical MDT meetings (consider tele-health) and/or provided with details of any decisions or changes in care arising from the MDT meeting
  - patients should be aware of the timeline for commencement of treatment
  - patients should be encouraged to participate in a program of prehabilitation (where suitable).

**Access and equity**

- Patients should have access to all treatments for CKD Stage 5, regardless of geographic location or other barriers such as literacy, CALD status, ethnicity, Aboriginal status and so on.
- Planning for renal services requires a focus on meeting local population health needs, and a focus on workforce flexibility and sustainability.
- Dialysis treatments should be delivered as close to home as possible.
- Providing access to home dialysis, or improving access to dialysis units closer to home will improve the health and HRQoL outcomes for people with CKD living in rural Victoria.
- Where home dialysis is not possible due to issues with place of residence (for example, renting, issues with water or power, house unsuitable, family not keen to have dialysis at home and so on), patients should have access to other local options for self-care dialysis.
- Access to local training facilities as well as implementation of alternatives to travelling significant distances to a metropolitan renal unit for routine dialysis or transplantation clinical assessments will improve options and outcomes for patients as well as enhance the patient experience.
- Utilising telemedicine to undertake some clinical consultation and assessment as well as facilitating case management meetings and other interventions for people in rural areas.

**Further information**

- KDIGO Guidelines
- IMPAKT study: improving health service delivery and outcomes for indigenous Australians with kidney disease
Suggestions for implementation

- Development and implementation of an agreed and standardised education Framework and syllabus for all services providing education to patients with CKD Stages 4 and 5.
- Unit investment in nurse practitioners to provide expert clinical care and management of patients including (but not limited to):
  - patient assessment, particularly for patients with complex healthcare issues
  - coordination and planning role to enhance consistency of care for patients with CKD
  - diagnosis and treatment, including prescribing necessary medications (as per the agreed formulary and within guidelines)
  - identification of clinical management and treatment options for patients
  - prevention of unnecessary referrals/admissions
  - provide clinical leadership and support workforce development.
- Explore options to utilise telehealth in order to improve access to specialist care for patients, particularly those living in rural and regional Victoria.
Step 4a: Treatment for CKD Stage 5: transplantation

Goals of care

- Timely referral to nephrology and transplant team.
- Early identification of all potential patients for transplantation, particularly pre-emptive transplantation.
- Early identification of potential living kidney donor.
- Early consideration of simultaneous pancreas kidney transplantation in suitable patients with Type 1 diabetes.
- Early identification of psychosocial issues and lifestyle modification.
- Ongoing monitoring and management of medication adherence.
- Management plan for donors requiring further investigations or additional support.

CKD Stage 5 is associated with the potential for kidney failure where residual kidney function may be insufficient to sustain life:

- CKD Stage 5: eGFR < 15 mL/min/1.73 m²

For the purposes of the RICP, the transplantation pathway commences at the point in time that the patient has chosen transplantation as their preferred treatment option.

Treatment options

1. **Deceased donor transplant.** In Australia, patients seeking a deceased kidney donor cannot be listed on the Australian Organ Matching Service (AOMS) database until such time as they have commenced dialysis therapy. AOMS listing can occur at any stage, but ideally should occur at the time of or shortly after commencement of dialysis. In Victoria, there is a KPI that measures time to AOMS listing and measures the proportion of patients (under the age of 65) listed within three or six months after commencement of dialysis.

2. **Living donor transplant.** Ideally, this will be pre-emptive (that is prior to need to commence dialysis). In many instances, the potential donor may not be biologically related to the recipient and may include a spouse, close friend, or, very occasionally, an altruistic donor (unknown to the recipient). New technologies and models of care (such as paired kidney exchange, the highly sensitised patients’ program, marginal kidney and ABO incompatible programs), as well as recent improvements in immunosuppressant therapies, are providing greater options for patients considering transplantation.

3. **Combined kidney and pancreas transplant.** For patients diagnosed with Type 1 diabetes who are approaching kidney failure or have commenced dialysis, and are aged less than 50 with no heart disease.
Providing good transplantation care

- Kidney transplantation should be considered for all patients likely to progress to Stage 5 CKD.
- Potential recipients should have access to all transplant treatment options subject to clinical and psychosocial suitability, and assessment.
- Reasons for patients being deemed unsuitable for transplant must be clearly explained to the patient and their family and documented in the medical record.
- Patients that may have clinical complexity or borderline in terms of suitability for transplant require a MDT discussion and assessment to determine suitability and plan their management.
- Clinically suitable patients choosing a deceased donor transplant should be placed on the AOMS wait list in a timely manner as per clinical guidelines.
- Potential recipients should be encouraged to undertake a program of prehabilitation
- Time in hospital should be minimised.
- Complications, side effects and comorbidity of kidney transplantation should be minimised.

Further information

- TSANZ Pancreas Protocol

Eligibility criteria

Currently, the number of patients who may benefit from transplantation is far greater than the number of organs donated, and the availability of donor organs is the limiting factor in applying organ transplantation as a therapy.

The Transplantation Society of Australia and New Zealand (TSANZ) has developed eligibility criteria for patients to be listed for organ transplantation and protocols for the allocation of organs to patients once listed. Organs from deceased donors are allocated to transplant recipients in a process that takes no account of race, religion, gender, social status, disability or age, unless age is relevant to the organ-matching criteria.

To be eligible to be listed for organ transplantation, patients must be referred for assessment and meet the eligibility following criteria:

- relative urgency of need
- medical factors which affect likelihood of success (for example, tissue matching)
- relative severity of illness and disability
- relative length of time on the waiting list
- likelihood that the recipient will (be able to) comply with the necessary ongoing treatment after transplantation.42
Extended criteria kidneys

Some donated kidneys can be difficult to allocate due to factors such as the donor’s age, health status and cause of death. Allocation of these ‘marginal’ kidneys of the donor can be challenging, and the process for matching these donations is currently under review within Victoria, with a view to providing greater clarity and consistency around the process for both transplanting services and potential recipients.

Ideally, discussions regarding the potential use of an extended criteria donation (ECD) occurs well in advance of the transplant so that patients and their carers and families have adequate time to consider the option.

Discussions should include full disclosure of the risks and benefits of an ECD, including expected impact on prognosis.

Patients choosing to not accept an ECD must not be disadvantaged in terms of their AOMS listing.

Transplant failure

• With the average life of a transplant being approximately eight years, early detection of and intervention for transplant failure is important.

• Patients should receive regular review and assessment, particularly in regards to ensuring adherence to their medication regime, as non-adherence is one of the major causes of graft loss.

• Strategies to address non-adherence to immunosuppressant medications as well as ongoing surveillance and intervention of modifiable health behaviours (for example, smoking, weight control, diet, exercise, mental health and so on) can reverse or slow down organ rejection. The inclusion of a renal pharmacist in the MDT may assist with managing medication adherence.

• Regular exercise supported by a renal rehabilitation program, will help minimise some of the side effects of immunosuppressant medications and should form part of any post transplantation care plan.

• Recipients experiencing chronic organ rejection must be linked back into the CKD pathway at an appropriate time in order to facilitate timely decision making of future course of treatment. Ideally, this is at least 12 months before anticipated transplant failure or as per the criteria based on eGFR, albuminuria and proteinuria.

• Treatment options may include: pre-emptive or deceased donor transplant (with or without AOMS listing), RSC or dialysis.

• Although a patient may have had dialysis or received CKD education in the past, it is inevitable that there have been many changes since that time and it is therefore essential that patients receive up-to-date information.

  • Refer to Step 3 – Preparation for Stage 5 CKD.

• Patients whose transplant is failing and for whom dialysis is not the best or appropriate option, may require end-of-life care support.

  • Refer to Step 5 – End-of-life care.

Patient concerns

Potential recipients worry that no organ will be available to them. They may fear the surgery or what living with someone else’s organ will feel like. They may have only a vague idea of what ongoing immunosuppressive therapy regime will entail. Asking family members to consider donating a kidney may also be difficult for some patients.

For families considering a living-related donation there are the concerns of organ compatibility, health impacts on the potential donor and the implications of being on the transplant waiting list.

Once transplanted, patients may have concerns regarding organ rejection, side effects from the immunosuppressant medications and adaptation to a ‘new’ lifestyle (often less restrictive in regards to time and diet compared to dialysis or advanced CKD).
The sudden loss of established social supports such as friendship groups established by recipients who have been receiving satellite dialysis, as well as the dramatic change in routine can be difficult for some. Others may experience feelings of guilt that they have received a transplant, while their dialysis friends are still waiting.

**Person-centred care and shared decision making**

Once patients have determined that transplantation is the best option for them, they may then need to make decisions about whether to accept or decline an organ offer or, as transplant function declines, whether to pursue re-transplantation or to move to dialysis, or RSC. It is essential that the transplant team provide the support and information needed to ensure the best outcome for patients and donors.

To achieve person-centred care and shared decision making:

- SDM should begin early in the assessment process, because understanding patient preferences is particularly important for patients on the transplant waiting list. Decisions regarding care and treatment may need to be made quickly should a kidney become available.
- Patients’ values and goals may change over time, therefore the transplant MDT should regularly review and update treatment preferences. This is especially important for patients on the AOMS waiting list.

Fact: Medical tests used to assess patient health and suitability for transplant includes (but is not limited to):

- a physical examination, including BMI assessment
- blood tests
- chest X-ray and electrocardiogram (ECG)
- cardiac imaging and assessment
- a surgical review
- tissue typing.

Source: Patient interviews 53

“Will I need to take immunosuppressants forever?”

“What will be the side effects of the drugs?”

“How long will it take for an organ to be available?”

“What happens if I miss the phone call?”

“What will be the impact on my relative/friend if they donate a kidney to me?”

Source: Patient interviews 53
Screening and assessment

• Early assessment provides more opportunity to address any health or psychosocial issues in a timely manner. This may, for example, include addressing issues of obesity, smoking, diabetes, CVD, mental health, pregnancies (or sexual health) or immunisations. Interventional support should be provided by the patient’s GP, their transplant nephrologist, transplant coordinator and relevant allied health workers.

• Patients should be supported to maintain physical and psychological readiness for transplantation. This is especially important for patients on the AOMS waiting list.

• Living donor work-up can take up to 12 months, with the timeframe generally guided by the potential donor. Donors should not feel pressured to donate, and should be fully aware of the risks and issues with the procedure to both themselves and the recipient.

• Early identification of patients who may benefit from a pancreas transplant (with or without a kidney transplant) is also important, along with timely referral for this treatment. Reassessment of suitability for transplantation should occur at regular intervals as part of routine care, even if the patient has commenced dialysis.

• In addition to ongoing monitoring and assessment of clinical suitability for transplantation, the transplant MDT should provide ongoing support for the patient in terms of maintaining their health and psychological status, regularly assessing the patient’s goals of care and expectations around quality of life which may change over time.

Post-transplant care

While many recipients will experience improvements in HRQoL and flexibility, they can experience many health issues related to the immunosuppressant drugs, including increased risk of skin cancers, CVD and bone disease. One of the major side effects of corticosteroids is osteoporosis, and this may be managed with a combination of medications and exercise.

Appropriate and ongoing assessment of patients, pre- and post-transplant, will ensure that issues can be identified and addressed in a timely manner. It will also assist renal services to better understand and plan their resource needs and to explore opportunities for service improvement and to achieve best practice in patient care.

Post-transplant assessment and monitoring requirements may include (but not limited to):

• care that is managed by the patient’s transplant surgeon for the first six months post-transplant; then, providing they are stable, referral back to their general nephrologist for ongoing care

Bright idea: Australia’s first seven-way paired kidney exchange

In November 2015, 14 Australians participated in an anonymous live kidney donation and transplantation exchange – the largest group of people to benefit from living donor matches at one time in Australia.

The Australian Kidney Exchange (AKX) Program uses a computer program to search the entire available database of registered recipient/donor pairs to look for combinations where the donor in an incompatible pair can be matched to a recipient in another pair. In each successful AKX match run, two or more simultaneous transplants can occur by exchanging donors.

The AKX program delivers good results for people who otherwise would have little chance of receiving a viable transplant, including some people with less than a one-in-a-hundred chance of receiving a kidney from a deceased organ donor, due to the difficulty of matching their blood and tissue type profiles.
• monitoring allograft function – as per agreed clinical guidelines
• prevention of non-adherence – educate all recipients and their families on the importance of medications and the risks associated with non-adherence. Consider increased screening for recipients with increased risks of non-adherence
• symptom burden assessment using validated and standardised instruments and assessment tools every three to six months
• vaccination – all recipients to receive vaccinations as per the clinical guidelines
• routine screening for new-onset diabetes, bone disease, cancer, hypertension
• monitoring of lifestyle related issues – obesity, smoking, drugs and alcohol and so on
  – consideration of sexual function and fertility
  – including issues of sexual dysfunction and infertility (male and female), pregnancy (including breastfeeding)
• mental health assessment – monitor and manage depression and anxiety\textsuperscript{43}

Further information
• KDIGO Clinical practice guidelines for the care of kidney transplant recipients
• KHA-CARI guidelines for care of kidney transplant recipients

Information and education
In Victoria, there is no standard course for pre- or post-transplant education or agreed syllabus. It is therefore difficult to determine the appropriateness and efficacy of transplant education programs currently provided, other than anecdotal feedback from patients and staff.

Ensuring that recipients have an appropriate level of health literacy with respect to the complexities of transplantation is important, because this will ensure that they have the skills and knowledge to make informed choices and understand the consequences of any actions that they may make in relation to their ongoing self-management.

Service providers need to ensure that:
• Initial education for potential transplant recipients may need to be commenced more than 12 months prior to the need for RRT, especially if pre-emptive transplantation is being considered.
• Patients require a combination of educational, behavioural and social support interventions to provide the best results for behaviour modification and ongoing adherence to treatment regimes.
• Education and information needs to be provided in a variety of formats such as one-on-one, group, written information or linkages to other organisation providing information and education.
• Strategies to improve medication adherence may include: simplified drug regimes, pillboxes to organise medications, individualised instructions (particularly for travellers and night-shift workers), or combining medication administration with daily routine activities.
• Greater use of digital media to broaden the delivery of patient education, as well as the development of an agreed core syllabus.
• Ongoing education for transplant recipients is important, although the amount and type of education will vary between individuals

Further information
• Appendix D: Elements of a successful education program
• Gordon et al., Opportunities for Shared Decision Making in Kidney Transplantation, 2013\textsuperscript{44}
Integrated care

- The patient’s GP can play an important role in helping patients manage their CKD, including ongoing management of other comorbidities and the initial transplant screening tests. The GP is responsible for timely referral through to specialist nephrologist to ensure adequate time for transplant work-up.

- Assessment and ongoing care of the transplant recipient requires input from a MDT that includes (but is not limited to), social work, dietetics, other allied health, psychology, advance practice nurse, or nurse practitioner, as well as coordination of care with other clinical specialities, especially if the patient has comorbidities such as diabetes, CVD, cancer or bone disease.

- Throughout the transplant pathway, patient self-management with support and involvement from the healthcare team is required. Patients should be linked to support services such as peer support groups, renal rehabilitation and, where relevant, programs such as HIP or HACC.

- At a service level, it is important that there are well-defined and transparent pathways for patients accessing CKD care in the community or at non-transplanting hubs to ensure appropriate coordination of care with one of the transplanting hubs services. This is particularly important for potential recipients living in rural and regional Victoria, or for specific groups of people such as Aboriginal and Torres Strait Islander populations or those from CALD backgrounds.

- End-of-life care should be provided in accordance with best practice as per step 5.

Figure 4 provides an overview of the core members of the transplant MDT.

 Depending on individual patient needs, other healthcare professionals may need to be included in the MDT.

 Depending on individual patient needs, other healthcare professionals may need to be included in the MDT.
Access and equity

- All potential recipients should have equitable access to transplantation regardless of point of referral and geographical location.
- They should be provided with clear and unambiguous care pathways including benefits and risks, along with an explanation of tests, procedures and results.
- In Victoria, renal service providers (transplanting and non-transplanting specialist renal services) work together to ensure that adults who are suitable for transplantation have timely access to this treatment.
- Opportunities to increase living and deceased donor rates should be explored, but may include improvements in referrals of potentially suitable candidates from general nephrologists through to the transplant centres, improved support for potential living donors, and more proactive programmatic support for patients needing to address lifestyle or other issues (for example, obesity, smoking cessation, other curable or modifiable diseases or psychosocial issues).
- Equitable access to transplantation should be available to all Victorians requiring and wanting this intervention, subject to clinical suitability. However, clinical suitability has sometimes been used to reduce transparency of decision making and to exclude the patients whose work-up may be more difficult and challenging. For example, medically suitable people should include those whose transplant work-up has been delayed by poor access to appropriate investigations such as coronary angiography.
- Psychosocial criteria are increasingly being included in practice guidelines for determining patient suitability for kidney transplantation. However, a national audit of all Australian transplant units found that the psychosocial criteria were often ill-defined and lacked substantiating evidence and recommendations for assessment or action, and that the use of psychosocial criteria in this manner decreases the transparency of patient selection and increases the potential for subjective estimates of social worth to influence patient selection.45

- A recent review of barriers to transplantation found that nine of the ten patients identified as suitable for transplantation, but not referred for consideration were from rural Victoria.46 The development of strategies and approaches to address the key issues preventing referral, such as improved education and support for rural and regional GPs and general nephrologists, streamlined pre-transplant work-up that minimises the requirement to attend the metropolitan transplanting hubs, regular visiting transplant teams to rural or regional locations, or addressing other barriers such as language or cultural issues may be required.
- For some regions, specific strategies targeted at improving access to transplantation for Aboriginal and Torres Strait Islanders may be necessary.
- All transplanting hubs require the necessary infrastructure to provide both deceased and living donor transplants. In addition, transplanting hubs should be able to provide access to paired exchange, ABO incompatible, and highly sensitised patients transplants. Transplanting hubs must also have clear criteria regarding acceptance and use of marginal kidneys.
- Transplanting hubs should actively collaborate with other non-transplanting hubs or local services in order to provide as much pre- and post-transplant care as close to the patient’s home as possible.
Further information

- TSANZSN Transplant organ allocation protocols

Suggestions for implementation

- Improve access to transplantation by implementing strategies to address identified barriers. Renal transplant services to actively participate in translational research.
- Patients to be better supported in lifestyle modification and rehabilitation.
- Ensure transplant recipients have access to ongoing post-transplant care to address issues such as change in lifestyle, psychological impacts, medication adherence and so on.
- For patients experiencing organ rejection:
  - ensure that there is an agreed plan for CKD management and early preparation for dialysis if appropriate
  - appropriate end-of-life care for patients is available, including access and support of palliative care.
Step 4b: Treatment for CKD Stage 5: dialysis

Goals of care

- Patient is well prepared for dialysis, including commencing on preferred modality and place of dialysis with a permanent access in place.
- Patient understands the risks, impacts and commitment required for dialysis treatment.
- Patient receives ongoing support and encouragement to maintain a healthy lifestyle with best possible HRQoL.

CKD Stage 5 is associated with the potential for kidney failure where residual kidney function maybe insufficient to sustain life:

- **CKD Stage 5: eGFR < 15 mL/min/1.73 m²**
- The aim of maintenance dialysis is to provide life-saving treatment to people with Stage 5 CKD. Patients requiring dialysis may be:
  - waiting for a suitable donor kidney for transplantation (on the AOMS waiting list)
  - unsuitable for a kidney transplant, and therefore have chosen dialysis as their preferred treatment option
  - returning to dialysis after transplant failure or commencing RSC.

For the purposes of this RICP, the dialysis pathway commences at the point in time at which the patient has chosen dialysis as their preferred treatment option. The choice of modality and treatment location is included in this step of the RICP.

**Treatment options**

Modality choice is typically determined by a combination of patient preference, absence of medical and surgical contraindications, and resource availability (this might include such things as location of nearest satellite service, suitability of a person’s place of residence for home dialysis and so on).47–49 

Patients on the dialysis pathway fall into two main categories:

1. those who have commenced dialysis, but are waiting for a transplant and therefore ‘temporary’
2. those for whom transplantation is not an option and therefore can be regarded as ‘long term’.

Management of patients receiving either mode of dialysis is essentially the same; however, those on the transplant waiting list will also require ongoing review and work-up targeted at maintaining the best possible opportunity for receipt of a donor kidney.

Similarly, the focus for those for whom transplantation is not an option should be on ensuring that they maintain a high level of wellness through lifestyle support and a focus on enhancing self-management, a good HRQoL and best possible functional and cognitive state over the longer term.

All patients should be offered the choice between home and facility-based dialysis. The choice of the specific dialysis modality is made after consultation between the clinician and the client, their carer(s) and family, and depends on many factors including availability of resources, place of residence, age, family support, overall health and lifestyle.
Where appropriate, patients should be encouraged to consider home-based therapies as a first option based on their:

- physical competency – able to demonstrate the ability to learn and perform HD or PD related physical tasks
- suitable physical environment (or not) when considering home-based therapies
- availability of family support
- comorbidities or other medical considerations
- clinical stability – level of need for ongoing clinical support
- cognitive skills competency – understand treatment requirements, have the capacity to undertake new learning, and to commit to ongoing care responsibilities.

Providing good dialysis care

- All patients with an eGFR of < 15 mL/min/1.73 m$^2$ must be managed by a dedicated renal service and appropriately structured and skilled MDT.
- Patients should have ideally participated in a program of renal prehabilitation.
- Patients requiring dialysis should have access to the treatment without delay.
- Patients on long-term dialysis should receive the therapy that will provide them with the best possible clinical outcomes and HRQoL.
- Patients should receive ongoing support to establish and maintain personal goals and objectives, as well as addressing barriers and negative attitudes to particular modalities through targeted and individualised information and explanation.
- Dialysis treatment should be undertaken in line with all relevant evidence-based clinical guidelines.
- Dialysis treatment should be focused on a rehabilitation model of care (MoC) and aim to enhance the patient’s HRQoL and wellbeing.
- Patients recognised by the MDT as ‘deteriorating despite dialysis’, and therefore approaching end of life, should be managed as per their ACP and receive appropriate end-of-life care.

Fact: Persons suitable for home dialysis include those who:

- are likely to be stable on dialysis
- have good functioning vascular access (for home HD)
- have appropriate family or carer support
- have a suitable home environment or access to other suitable facilities in which to dialyse
- have the necessary level of motivation and confidence to undertake home dialysis.

Withdrawal of dialysis

Patients receiving dialysis may, at some point, be struggling to maintain a good HRQoL as a consequence of progressive deterioration in clinical status or sudden onset terminal event or life-limiting diagnosis, such as a cardiac episode or stroke. Patients need to be recognised as approaching end of life, and an appropriate plan implemented for withdrawal from dialysis and end-of-life care, which may include withdrawal of dialysis.

The decision to cease dialysis should be a joint decision between the patient and their family and the MDT. It should be facilitated by the advance directives included in the patient’s ACP. It may also be appropriate at this stage to engage with palliative care or other support services such as HIP.

See also Step 5 – End-of-life Care.

Further information

- KHA-CARI Dialysis Guidelines
- KDIGO Guidelines
Patient concerns

Dialysis is a daunting prospect for many people, especially given the impact on lifestyle and wellbeing. For those patients who have made an (informed) decision to commence dialysis, there is likely to be a range of concerns as they adjust to the impending commencement of their treatment.

Concerns may be about the logistics of dialysis: ‘Where will I get my dialysis?’ ‘How will I get to the satellite unit?’ Other concerns may be about the impact of dialysis on their quality of life or their family: ‘Who will look after my family while I attend home dialysis training?’ ‘How will I manage holidays or other travel requirements?’ Some concerns may be about the treatment itself: ‘How do I care for my Tenckhoff or AV Fistula?’ ‘How will my diet and fluid intake be affected?’ ‘How long will the treatment be effective?’

Irrespective of the issues, patients and their families must be made to feel comfortable about expressing their concerns to their care providers. Open, honest and clear channels of communication will help to relieve anxieties and help provide an enhanced patient experience.

It is also been found that although health professionals have a good understanding of patient concerns about the clinical effects of CKD and dialysis, it is apparent that patient concerns regarding HRQoL are not fully appreciated by clinical staff, including relationships with staff, diet, scheduling, symptoms and self-care issues.53

Person-centred care and shared decision making

All patients and their carers and families need to be actively involved in the decision-making process regarding their ongoing care and treatment options. This includes the opportunity to regularly review modality choice, particularly after they have been dialysing for a few months or when there are significant changes in their health or personal circumstances.

“I was depressed when told I need HD. I was very restless, anxious scared of the first day of HD because of needling and the routine...”

“A shock initially, hearing news of kidney failure. My partner was worried about my food and fluid consumption...”

“I was overwhelmed and daunted about PD at first. However, later when trained and back home everything made sense...”

Source: Patient interviews 53
Decisions should be determined on the basis of the patient’s values and preferences, the patient’s clinical condition (comorbidities and so on) and expert clinical evaluation of the patient’s prognosis.

Where appropriate, patients should be informed that dialysis may not result in a survival advantage or improve functional status over medical management without dialysis (RSC).

Patients who have commenced dialysis should have their option choice reviewed within three months of commencement.

Should the chosen modality be not meeting patient and MDT outcome expectations, the patient should receive further education and information to assist in the selection of an alternative option.

Patients choosing dialysis need to be better supported to be independent in their care. This can be achieved through key strategies, such as:

- improved training for patients that incorporates greater levels of flexibility to cater to individual needs, better use of existing resources (for example, staff in rural renal satellites) and a greater commitment to self-care dialysis from renal services
- consideration of new models of care such as self-care community-based dialysis for patients unable or un-willing to dialyse at home.

**Further information**

- [Department of Health, Guide to implementing person-centred practice in your health service](#)
- [Office of the Public Advocate for Power of Attorney](#)

**Screening and assessment**

Patients receiving dialysis will face lifelong physical, psychosocial, and other social problems related to their illness and treatment. Patients regularly report that they feel anxious, fearful, depressed or stressed, and that their disease and treatment has significant impacts on their quality of life, financial status and general social functioning.

- Ongoing screening and assessment that captures changes in physical, chemical, mental and personal status is part of good quality routine care for patients on dialysis and is essential. Ideally:
  - screening should be undertaken using validated tools or patient self-report
  - assessment should be undertaken using validated tools
  - all patients will receive a baseline assessment of their physical, functional, cognitive, mental health and socioeconomic status prior to commencement of dialysis.

- Patients will be routinely reassessed on a regular basis (ideally annually), or where the patient has experienced a significant change in health or personal status.

- Every person receiving dialysis treatment should have their kidney disease symptom burden assessed using validated and standardised instruments and assessment tools every three to six months.

- Patients receiving facility-based dialysis are routinely reassessed for their suitability for home dialysis and actively supported to overcome any modifiable issues or barriers.

- Physical and psychological symptoms are routinely and regularly assessed and actively managed.

The VRCN, in collaboration with the renal sector, is currently undertaking a project that aims to identify a process for comprehensive patient assessment for Victorians with Stages 4 and 5 CKD. The final outcome of this project is expected to be available by early 2017.
Further information

- KHA-CARI dialysis guidelines
- KDIGO Guidelines
- Renal Resource Centre, NSW. Health Management Plan For End Stage Kidney Disease

Information and education

- Patient education is ongoing and occurs at every interaction with the care team. Education may be formal through specific classes led by an expert dialysis educator, as well as self-education, often utilising online resources.
- While, for most patients, the majority of their formal CKD education will occur prior to the commencement of dialysis, it is important that patient education continues to address any changing needs, especially if the patient’s condition is deteriorating and dialysis is no longer providing effective treatment and a good HRQoL.
- Currently, renal services in Victoria do not routinely provide any formal education to patients once they have commenced dialysis. Patients have indicated that further formal education post the commencement of dialysis would be useful if it were focused on the practicalities of ‘living with dialysis’.
- Education programs need to be tailored to the individual patient and based on the principles of adult learning and health literacy. Information needs to be delivered in a way that is accessible to the patient, including delivery method, pace of delivery and location of programs, and be relevant to the stage of treatment and their current life stage.
- It is essential that the educational content of CKD patient information is based on accepted evidence and an agreed core curricula that is grounded in learning principles specific to the age of the patient.
- E-learning is now widely used in many settings to provide accessible and tailored information and education. Online education for patients and their families has the potential to facilitate greater accessibility, especially for those living in rural Victoria or those with language issues or other disabilities. E-learning can be provided as prepacked modules of information allowing patients and families to work through the information at their own pace, or provided in real time through interactive video-conferencing.
- Patients choosing home dialysis require sufficient education and training for themselves and their carer(s) to ensure that they can dialyse at home safely and confidently. The role of home dialysis staff is that of an educator and support person. The home dialysis patient needs to be self-aware of what is safe and when to seek help.
- For patients considering changing their treatment modality, it is essential that they receive detailed and comprehensive information about the options available to them. This should include how changing modalities may impact future treatment options.

Information about dialysis should be balanced and accurate and include:

- a detailed description of all treatment modalities, (even if the renal service does not offer all options), including:
  - potential benefits to the individual
  - prognosis
  - risks
  - potential side effects and their impacts.
• An individualised discussion of the treatment that includes:
  – maintaining activities of daily living, such as work, education, family responsibilities, hobbies, travel, social interaction and so on
  – likely impact on the patient and their family
  – impact on body image
  – any requirements for home modification
  – financial costs associated with dialysis, including, transport, power and water, consumables, medications and so on
  – flexibility of treatment regime
  – additional support services that may be required.

Further information
• KHA-CARI dialysis guidelines
• KDIGO Guidelines
• KHA Fact sheets
• Renal Web

Integrated care
Given the complexity of dialysis treatment, patients generally require the support and input from a variety of clinicians with a range of specialist skills and knowledge. Ideally, clinicians will work together as a part of a MDT (see Figure 5) to coordinate care for the patient. Many patients with CKD also have other comorbidities which may have precipitated their kidney failure (diabetes, CVD and so on). On addition, some will have developed complications and comorbidities as a consequence of their CKD (CVD, cancer, bones disease and so on). New models of care or workforce models (such as the advance practice nurse, nephrology nurse practitioner, chronic disease management nurse practitioner and so on) provide opportunities to develop a more integrated approach to patient care.

Patients choosing dialysis as their preferred treatment option require the coordinated input of surgical intervention for timely access surgery, as well as ongoing communication and coordination of care between healthcare providers to facilitate a proactive approach to maintain quality of care and minimise risks such as technique failure, infections or other treatment-related complications.

Members of the MDT, such as nurses, dieticians and physiotherapists are encouraged to maximise their knowledge and skills across disease areas to influence and improve outcomes of those with CKD and Stage 5 CKD. In particular, management of fluid balance, blood pressure control and monitoring, discussion of blood results and reduction of cardiovascular risk factors.

Advanced care renal nurse
Advanced care renal nurses provide an integrated model of care, especially for patients with complex health needs. Advanced care nurses conduct comprehensive physical assessments and formulate plans of care as well as provide referrals to specialists, and support patients who are waiting for or who have received kidney transplants. Advanced care nurses may also provide assessment and intervention for patients requiring end-of-life care and refer patients with end-stage renal disease for hospice services.
Depending on individual patient needs, other healthcare professionals may need to be included in the MDT.

Patients receiving dialysis treatment should be provided information and support by the MDT to access appropriate support services; for example, Health Independence Programs (HIP), Home and Community Care (HACC), short-term supports (for example, respite or inpatient care), as well as appropriate end-of-life care for patients for whom dialysis is no longer providing improved clinical outcomes or HRQoL.

Further information
- KHA-CARI – Multidisciplinary or multifaceted renal care in early chronic kidney disease
- Life Options – USA
Access and equity

Studies have shown that major barriers to the uptake of RRT in general, but also home haemodialysis (HHD) more specifically by people living in rural Australia, is distance and travel, access to reliable power and water and access to education and training (especially for HHD). Patients require coordinated and accessible care, and this means that renal services will need to look at how the structure of the current system is meeting population health needs and consider opportunities to:

• use available infrastructure more efficiently
• improve opportunities for technical and other non-clinical support
• improve capacity for consumer engagement and involvement in service planning and service delivery
• improve referral pathways and working arrangements with GPs and other community-support services (for example, HACC, aged care, post-acute care and so on).

Further information


Improving care for patients on dialysis

It is recognised that patients on long-term dialysis can face many issues and constraints which are not necessarily evident or as significant for patients on other treatment modalities or in earlier stages of CKD. The following sections discuss and respond to some of the key issues raised by patients and clinicians that were interviewed as part of the development of the dialysis pathway for the RICP. However, it is acknowledged that the issues raised by the patients receiving dialysis, may also be applicable to other people with CKD.

Respite

Patients have indicated how beneficial it would be to be able to access respite services in order to give themselves and/or their carer a break. Several patients interviewed as part of the development of the renal pathway indicated that they were reluctant to take up HHD due to the significant burden that this would place on their family or carer (typically their spouse). Several patients were concerned that, once committed to this regime, there were limited opportunities for respite for either themselves or their carer.

Some nephrologists also indicated that they would offer home dialysis to more patients if services such as respite (amongst others) were more readily available.

Renal services should actively support patients to access respite services which may be through established services such as HACC or aged care, or through developing or enhancing respite support through their renal service.

Carer support

Dialysis requires considerable commitment from patients, their carers and their families, particularly as many patients have other comorbidities along with their CKD. Irrespective of the mode of dialysis, patients may need assistance to get to and from their place of treatment, attend medical appointments or undertake the dialysis treatment. Importantly, though, carers and other family members provide psychological, emotional and financial support to the patient, and typically take on a far greater role in supporting the day-to-day requirements of running a household.
Carer burden can increase significantly as the patient functionally and cognitively declines and their ability to care for themselves reduces. Patients may need to rely increasingly on family to support them as they age and experience issues such as visual decline, reduction in manual dexterity, lose the ability to drive safely, experience mood disorders or other cognitive disorders such as dementia.

Supporting carers as well as patients is essential. This should include:

- health service staff actively monitoring and supporting carers to ensure that they are coping with the additional workload and the emotional aspects of caring for a family member with CKD
- ensuring carers are aware of and have access to support programs including respite care to provide carers the opportunity for a break.

Further information
- Carers Victoria
- Department of Social Services, Australia
  Respite Care Program
- Victorian Carer Services Network

Bright idea: Respite in the renal care setting

Two Victorian hubs have recently implemented programs that provide respite or in-home support for patients. Eastern Health implemented an assisted program for respite care for home patients as well as a program, whereby patients currently receiving APD can receive that care staying overnight at the hospital’s training facility. Austin Health implemented a program to support PD patients by training Royal District Nursing Service (RDNS) nurses so that they can provide in-home support services to patients with temporary difficulties or whose carer is temporarily unavailable. Evaluations of these programs found that their patients and their carers and family have reported benefits such as improved patient satisfaction.

The Away From Home Haemodialysis (AFHH) Program in NSW provides a respite service for HD patients living in NSW. Managed by EnableNSW, eligible patients can access up to three free sessions a year at participating private renal units located throughout Australia and New Zealand, at no cost. The respite can be used for any reason including, work, education, holidays or any other personal reason.
**Transport for dialysis patients:**

Persons who travel to receive routine maintenance dialysis can be divided into four broad transport categories:

1. those who walk to dialysis (a small percentage)
2. those who drive or are driven in a private car or taxi
3. those who travel by public transport (bus, train)
4. those who use hospital-arranged transport (for example, ambulance, a multi-occupancy vehicle or a car).

Transport for people with Stage 5 CKD is a key consideration that may impact choice of treatment, and it is an issue that often causes concerns, risk and anxiety.

To ease some of the risks and stressors associated with transport to and from dialysis facilities, patients should:

- attend the dialysis unit as close to their home as possible (subject to availability)
- be provided with free or discounted parking while attending for maintenance dialysis
- be aware that if they are driving to and from dialysis, they are safe and competent to do so
- not drive themselves to dialysis for their first few sessions or until such time as they have acclimated to the treatment
- be supported to access all available travel assistance, including government transport subsidy schemes, taxis, ambulance, public transport, community transport services, hospital volunteer services and so on
- be encouraged to consider home dialysis if clinically suitable.

**Travel and holiday**

The benefits of travel are well documented and, like the general population, people receiving maintenance dialysis can significantly benefit from being able to have holidays and travel. This may include improved mental and physical health. Holiday dialysis for persons receiving either facility or home-based dialysis often requires careful forward planning. For those on HD this can also include negotiations around the availability of dialysis chairs at other satellite services. For those persons on PD, arranging travel can also be a significant logistical exercise; however, it is typically well supported by the PD suppliers.

The three key issues for holidays and travel cited by patients that are most difficult for them were:

1. risk of infection (particularly for those patients from less-developed countries)
2. logistical obstacles to arranging travel
3. cost.

Patients on dialysis treatment currently have access to several holiday options arranged and managed by peak bodies including KHA and the Dialysis and Transplant Association (DATA), including holiday houses, the Big Red Kidney Mobile Dialysis Bus and other holiday support. Private dialysis services also provide holiday advice and support, along with several private tour operators that offer access to cruises and other assisted travel arrangements.

Public dialysis units should, accommodate those seeking holiday dialysis where possible.

**Further information**

- KHA, Transport options for dialysis in Victoria
Patients should be provided with information and support to improve access to holiday dialysis, which may include providing:

- information about reciprocal health and hospital care arrangements with other countries (for example, Netherlands, New Zealand and the United Kingdom)
- collaboration with private dialysis providers, which generally have greater capacity to provide holiday dialysis.

Further information
- Kidney Health Australia
- Dialysis and Transplant Association Victoria
- KHA, Holidaying on dialysis

Suggestions for implementation
- Explore opportunities for best use of technology to improve patient self-management and monitoring.
- Reduce the need for travel to receive education or clinical consultation through better use of tele-health and outreach services.
- Explore new models of care that provide greater accessibility and support for patients (for example, community-based self-care, assisted home dialysis, respite care).
- Continue the development and expansion of the nurse practitioner role to assist with management of patients with complex healthcare needs.
- Develop and implement a statewide database across all renal health services to enhance patient care and service integration.
- Encourage greater awareness of environmentally sustainable practices and policies within the renal health setting, including the patients’ homes.
Step 4c: Treatment of CKD Stage 5: renal supportive care

Goals of care
Renal supportive care integrates renal and palliative care and other services to provide:
- improved care for patients with CKD or who are not having dialysis or transplantation
- a better patient and family experience
- greater choice and autonomy around decision making regarding whether to commence or discontinue dialysis
- better disease control and symptom management for patients on either a supportive or dialysis pathway
- enhanced coordination of care for patients with both CKD Stage 5 and another life-limiting disease such as cancer.

CKD Stage 5 is associated with the potential for kidney failure where residual kidney function maybe insufficient to sustain life:
- CKD Stage 5: eGFR < 15 mL/min/1.73 m²

For the purposes of the RICP, the renal supportive care (RSC) pathway commences at the point in time that the patient has chosen RSC as their preferred treatment option.

Renal supportive care (RSC; also known as ‘conservative care’ or ‘non-dialytic management/therapy/treatment’) is generally understood to encompass the care and treatment of people with CKD who do not have dialysis or transplantation but whose kidney and any comorbid disease, is medically managed with particular emphasis on:
- symptom management
- psychological and social support
- advance care planning
- end-of-life care
- bereavement support.

It encompasses the appropriate and careful management of:
- specific advanced CKD symptoms of anaemia
- metabolic bone disease
- blood pressure management
- blood glucose control
- electrolyte abnormality
- symptoms of uraemia.

Treatment options
For some people with other serious illnesses as well as kidney failure, transplantation is not a reasonable option, and dialysis may make little difference to survival prognosis or HRQoL. It is important to understand that dialysis can be very difficult for some people and a ‘no dialysis’ option may give a better HRQoL than dialysis.

There are two main groups of people that may be suitable for RSC:
1. those who choose to not commence dialysis or transplantation
2. those who choose to discontinue dialysis or transplantation treatment (although it is noted that many of these patients will have an imminent death and should therefore be managed as per the end-of-life pathway).

It is absolutely imperative that RSC is not seen as a no treatment option, and that a RSC treatment program include all treatment strategies that promote optimal physical and psychosocial wellbeing and HRQoL, while excluding treatment that the patient accepts as unsuitable, potentially burdensome and non-beneficial; that is, transplantation or dialysis. Patients (and their families and carers) who opt for RSC must have a clear understanding of what treatment strategies will be beneficial for them and hence be assured that they will be treated and cared for appropriately. RSC is medically managed with particular emphasis on:
- symptom management
- psychological and social support
- advance care planning
• end-of-life care
• bereavement support.

Ideally, RSC treatment should be provided through a specific RSC program that links renal services with other programs areas such as the Health Independence Program (HIP), palliative care, gerontology, cardiology and so on.

The decision to opt for RSC must not be considered irrevocable, and those who choose RSC should have the option to revisit a discussion about alternative treatment options with their treating nephrologist. In some instances, it may be possible to choose a different treatment option, including dialysis.

Providing good renal supportive care
• Patients receiving RSC must continue to receive appropriate management of their CKD as well as any other interventions that will assist in the management of any other comorbidities.
• There should be effective referral system to ensure effective care coordination and communication pathways between renal health professionals, GPs, primary care, palliative care teams and other health services (for example, community nursing). This is essential in order to provide streamlined person-centred care and effective use of health and human resources.42
• A lead agency for care coordination should be nominated. Depending on the patient’s expressed wishes, complexity of a patient’s needs and prognosis, this may or may not be the renal team. Regular review and assessment that incorporate case conferencing with the renal MDT and the palliative care team should occur:
  – years or months to live – three-monthly
  – months or weeks to live – monthly
  – weeks or days to live – refer to end-of-life care.
• The medical management of patients receiving RSC should include ongoing monitoring of:
  – specific advanced CKD symptoms of anaemia or uraemia
  – metabolic bone disease
  – blood pressure management
  – blood glucose control
  – electrolyte abnormality.55

In addition it is important to manage:
• diet – patients on RSC will significantly benefit from particular attention to what they eat
• anaemia – anaemia is an important part of the symptoms of renal failure. Treatment of this can include management strategies used to treat anaemia in patients receiving dialysis, including erythropoiesis stimulating agents (ESAs), and blood transfusions if necessary
• symptoms – including fluid control, pain, pruritus, tiredness as well as any other psycho-social issues.

Eligibility criteria
Those who may not be suitable for dialysis or transplantation usually have other serious illnesses as well as kidney disease, which may include:
• severe chronic heart or lung disease
• severe peripheral vascular disease
• advanced cancer
• dementia.

The very elderly are more likely to find dialysis difficult, but age in itself should not preclude considerations of other treatment options.

Withdrawal of treatment
RSC is not specifically end-of-life care, because people can live for months or years on the RSC pathway.

RSC is never withdrawn, but care and treatment priorities may be reassessed, particularly if death is imminent.

See also Step 5 – End-of-life Care.
Patient concerns
It is important that RSC is conveyed to patients as a valid treatment option for their advanced CKD. Patients may be concerned about what will happen to them should they choose this option and whether their renal care team will continue to look after them.

Patients need to be reassured that RSC is not end-of-life care, and that many people can live for months or years with minimal kidney function.

Patients and their carers and family may also be concerned that their decision to choose RSC treatment is irrevocable, so need to be reassured that they may, at any time, discuss alternative treatment options with their treating nephrologist and, in some instances, it may be possible to choose a different treatment option.

Further information
- Royal Australian College of General Practitioners
- Renal Resource Centre, An introduction to conservative care of advanced kidney disease
- Palliative Care Victoria

Person-centred care and shared decision making
The decision to have RSC for CKD Stage 5 should be made by the person (and/or family/carers) in collaboration with their care team. This should be undertaken through a process by which clinicians and the person (and their families/carers) work together to select the preferred or most appropriate treatment and management options. Having discussed the options and their benefits and harms, along with consideration of the person’s values, preferences and circumstances, the person’s goals of care can be determined. This will be achieved by:

- honest engagement with the person and their family/carers
- engagement and collaboration with the person’s general practitioner
- communication and support for the person and family/carers
- maximising functionality

“Do many people make this decision and choose this option?”
“Do many people make this decision and choose this option?”

Source: Patient interviews 59

“If I choose to not have dialysis or transportation, will my renal team still look after me?”
“If I choose this option, can I change my mind and have dialysis?”

Source: Patient interviews 59
• active medical management of the problems associated with kidney failure, (such as anaemia and vitamin D deficiency, as well as management of blood pressure, fluid balance, and calcium and phosphate levels alongside treatment of acidosis and hyperkalaemia as indicated) and comorbid disease (such as diabetes, heart disease)
• routine assessment of symptoms and psychosocial situation
• multidisciplinary management of the person’s care
• management plans for symptom management
• appropriate referral to other services; that is, palliative consultancy services, community palliative care, community services
• advance care planning in place and ongoing with Medical Enduring Power of Attorney (MEPoA)
• preparation and planning for end of life.

Screening and assessment

• People receiving RSC need to be routinely screened using a validated screening tool or suite of tools. Any identified issues should then be comprehensively assessed, and interventions planned and activated. If necessary the person should be referred to appropriate health professionals, services or organisations to meet their needs and those of their family/carers.

Screening and assessment should include:
  - performance or functional status
  - physical symptoms
  - depression and mental health
  - cognition
  - quality of life
  - psychosocial issues.

• It is important that those who elect to decline dialysis treatment are not severely depressed and that they are fully aware of the consequences of such a decision. Therefore, appropriate assessment of cognitive and mental health status is recommended.
• Aboriginal and Torres Strait Islander people and patients from other cultures may hold particular views or beliefs around treatment choice and RSC. The MDT should ensure that they are aware of individual beliefs and values and that these are respected at all times, even if they do not reflect the views and opinions of members of the MDT.

The VRCN is currently undertaking a project with the renal health sector to develop an agreed suite of screening and assessment tools, based on existing validated tools. This project should be completed by early 2017.

Further information

• ANZSN Renal supportive care guideline 2013
• Koolin Balit, Victorian Government strategic directions for Aboriginal health, 2012–2022

Fact: The ANZSN renal supportive care position statement 2013 states that it reasonable to consider a non-dialysis pathway where there are two or more of the following factors when assessing the potential for dialysis in a patient over 75:

• nephrologist response to the surprise question of ‘I would not be surprised if my patient died within the next 12 months’.
• high comorbidity score (for example, modified Charlson score ≥ 8).
• marked functional impairment (for example, Karnofsky performance status score < 40).
• severe chronic malnutrition (chronic serum albumin < 25 g/L).
Integrated care

- The provision of RSC to people choosing not to undertake dialysis or transplantation requires a MDT approach to care. The MDT should include: nephrologists; renal nurses/nurse practitioners; primary care (GP and community support services); palliative care clinicians; allied health; and pastoral care (see Figure 6).
- With an ageing population, it is likely that the numbers of people choosing a RSC pathway will increase and renal services will invariably have far greater input into the management of this patient group. Having appropriately skilled and trained staff as part of the renal MDT will enhance the care and treatment of all patients through a greater awareness of the value of a supportive approach to patient management.
- There should be effective referral and communication pathways between renal health professionals, general practitioners, palliative care teams and other health services as required.

Patients will benefit by having access to renal clinicians who are trained and skilled to manage patients on RSC.

Patients will benefit through the development of partnerships between renal and palliative care services by:
- specific RSC clinics run by palliative care health professionals (medical and nursing) for people with difficult symptoms
- attendance by palliative care specialists at renal MDT meetings when the care of people with CKD who have opted not to have dialysis or transplantation or who have a high symptom burden is discussed.

Further information

- ANZSN Renal supportive care guideline 2013
- Program of Experience in the Palliative Approach (PEPA)
- Palliative Care Australia & Kidney Health Australia, Palliative care for chronic and end-stage kidney disease; position statement

Figure 6: Core members of the RSC MDT

Depending on individual patient needs, other healthcare professionals may need to be included in the MDT.
Information and education
Renal services and health professionals need to ensure that RSC is offered as a clinically supported option to dialysis and transplantation. Renal health professionals need to be knowledgeable about:

- renal supportive care
- what community services or inpatient and community palliative care can provide
- how referrals can be made to inpatient and community services, including palliative care
- the benefit to patients with CKD of referral to palliative care services.
- how religious and cultural beliefs may influence a patient’s view on medical decision making, including withholding or withdrawing dialysis.

Family meetings with medical and other staff are useful in helping family members to understand all factors involved and to weigh up the benefits and burdens of dialysis treatment versus RSC.

To enhance the understanding of RSC requirements with the Victorian community, renal services should collect data and information about people who do not have dialysis or transplantation but are registered with a renal service. Ideally, this data would be included within the existing Victorian Dialysis Registry and the national ANZDATA registry.

The VRCN, in collaboration with the renal sector, is currently undertaking a project that aims to identify a process for comprehensive patient assessment for Victorians with Stages 4 and 5 CKD. The final outcome of this project is expected to be available by early 2017.

Further information
- Advance Care Planning Australia
- RSC education package

Access and equity
Recognising that not all patients will be able to access RSC services close to where they live, renal services should consider providing a consultancy or a support service to the patient’s local care providers to minimise unnecessary travel. This may include the patient’s GP, residential care provider, local hospital, community care organisation, or other local service.

Patients residing in rural areas are often economically and medically disadvantaged compared to their metropolitan counterparts, when it comes to accessing healthcare services, particularly specialist services. A proactive approach to addressing this inequality will improve patient outcomes. By providing support to local GPs and other healthcare providers, patients will be able to have improved access to appropriate care and treatment close to where they live. Models of care may comprise: outreach, a RSC consultancy model.

Greater use of tele-medicine will enhance the patient experience and increase local capability. It is also important that renal services are aware of what services are provided within the catchment areas of their patients.

Further information
- ANZSN Renal Supportive Care Guidelines 2013
- PEPA Program

iii Noting that renal services may require additional resources to do this.
Suggestions for implementation

1. Regular and routine screening and assessment using validated tools (that have been ‘accepted’ across Victorian renal services) should be undertaken with all people with CKD who do not have dialysis or transplantation so that: their needs can be identified and addressed; current resources can be optimised; future resource requirements can be informed and quality services can be developed and maintained.

2. Review of renal service funding models so that RSC becomes a funded activity within the trajectory of CKD, which will ensure that there is equity of access to RSC for all people with CKD who opt not to have dialysis or transplantation.

3. Data/information should be collected by the Victorian Dialysis Registry and the national ANZDATA about people who do not have dialysis or transplantation but are registered with a renal service.

4. RSC clinics within renal services (for example, nephrology nurse practitioner led).

5. Partnerships between renal and palliative care services by:
   (a) specific RSC clinics run by palliative care health professionals (medical and nursing) for people with difficult symptoms
   (b) attendance by palliative care specialists at renal multidisciplinary team meetings when the care of people with CKD who have opted not to have dialysis or transplantation or who have a high symptom burden is discussed.

6. Formal evaluation of RSC models and initiatives.

7. Effective referral systems between renal services and hospital consultancy palliative care service.

8. Ongoing education about RSC for renal health professionals.

9. Ongoing PEPA (Program for Experiencing the Palliative Approach) placements for renal health professionals.

10. Possible reverse PEPA placements where palliative care professionals spend time in renal services to help inform and embed a supportive approach to chronic disease.

11. Education and training in communication skills, including role play (especially around discussion of prognosis) for renal health professionals.

12. Development of a key performance indicator (KPI) about RSC that can be incorporated in the Victorian Renal KPI dataset to measure and ensure quality in renal services, specifically RSC.

13. There should be effective referral and communication pathways between renal health professionals, general practitioners and palliative care teams in order to provide streamlined care and effective use of health and human resources (Palliative Care Australia and Kidney Health Australia, 2014).

14. Advance care planning should be offered to all people with CKD.
Bright idea: Capacity building Victorian renal services for renal supportive care

In 2014 the Victorian Department of Health and Human Services committed funding for RSC capacity building to each of the ten renal hubs in Victoria. The amount was determined by the proportion of patients at each renal hub. The funding made available to each of the renal hubs was to assist in the following capacity building activities:

- strengthening of the relationship between palliative care and renal services
- supporting review of educational and information resources available for patients, carers and health professionals, with revision where necessary to ensure information about renal supportive care and symptoms of renal disease is included
- providing education to ensure renal clinicians are knowledgeable about RSC. This will support change in the health service culture to recognise RSC as a clinically supported alternative to dialysis and transplantation
- introduction of functional and symptom burden assessment of all renal patients over the age of 65 using the Australian modified Karnofsky performance scale and the POS-S renal every six months. This will include patient on dialysis and those attending chronic kidney disease clinics with an eGFR < 15
- enabling of at least two staff members (nursing/allied health/medical) to participate in a Program for Experiencing the Palliative Approach (PEPA) placement.
Step 5: End-of-life care

Goals of care

Quality end-of-life care is provided to enable the patient to:

- recognise that the end-of-life phase is approaching so that end of life can be planned and appropriately supported
- die with dignity in a setting of their own choice with a jointly agreed palliative care plan built around individual needs and preferences
- have their care needs provided in a planned and agreed manner that minimises distress, unnecessary symptom burden and poor QoL.

End-of-life care is defined as care for those who are imminently dying (that is, may only have days or weeks to live).

This may occur:

- following a decision to stop dialysis, or not to initiate or recommence dialysis after a failing or failed transplant
- with deterioration despite dialysis from either CKD or other comorbid conditions
- as a natural progression of deteriorating CKD for those people who are receiving RSC.

End-of-life care is not a desire to bring about the patient’s death, and prolonging life should always be the first goal of the care team. However, this should be tempered with the consequences and impact of treatment on the patient, as well as the patient’s views, if they are known or can be found out.

Providing good end-of-life care

- Good end-of-life care includes:
  - ensuring the patient is involved in discussions about care as far as they are able
  - end-of-life discussions with the patient and the family and carers to provide support and education about end-of-life and bereavement support
  - spiritual care
  - initiating observations for common end-of-life symptoms, such as restlessness, pain, nausea and breathlessness in order to provide timely symptom management
  - reviewing and ceasing all non-essential medications and interventions
  - impeccable assessment of symptoms.¹²

- Consideration should be given to caring for the patient in such a way that suffering is not prolonged unnecessarily. This may involve discontinuing unnecessary treatments or medications, avoiding invasive testing and complying with the patient advance care directives.

- Ensure that all people with CKD who are imminently dying have an end-of-life care plan.

- Ensure that all people with CKD who are imminently dying have the opportunity to die where they wish with the support and care they need.

- Ensure that families/carers of people with CKD who are at the end of life or who have died have access to bereavement services. Information regarding bereavement services should be provided in written format.

- Renal health services should develop practices and processes that include:
  - timely recognition that the person is at or approaching end of life to ensure that an end-of-life plan can be developed and put in place in a timely manner
  - access to, collaboration with, and referral (when appropriate) to palliative care services.
  - access to multidisciplinary teams within the health services and multidisciplinary team meetings in which the care of people who are at the end of life is discussed
– effective communication processes between renal service providers, the person’s GP, palliative care services and other community services
– access and opportunity for review of ACP
– referral to appropriate community services, such as: community care, Royal District Nursing Services or other community nursing services and community palliative care.59

Dying is a normal part of the human lifecycle, and something that everyone will experience. Dying should not be regarded as a medical or biological event, but a time for compassion, empathy and emotional support. Good clinical care will ensure that the patient’s physical needs are appropriately met and that the inevitability of dying occurs in a respectful, sympathetic and caring manner in accordance with the wishes of the patient and their carers and family.

**Identifying end of life**

Recognition of imminent end of life which, for those who withdraw from dialysis, can be a matter of days, but for those on a supportive care pathway or who are deteriorating despite dialysis, it may be months. Recognition of the end-of-life phase is a trigger to initiate palliative care discussions and the referral to specialist palliative care services for in hospital and community support with the person and their family/carers about providing symptom management, comfort measures with a focus on quality of life, and support through the continued provision of skilled medical, nursing and allied healthcare.

The aim of quality end-of-life care is to enable the person to die with dignity in a setting of their own choice with a jointly agreed palliative care plan built around their individual needs and preferences.

There needs to be:

- timely recognition that the end-of-life phase is approaching
- sensitive communication with people and their family/carers
- holistic assessment which includes the needs of carers
- joined-up planning and effective multi-professionals working across boundaries linking kidney care, primary care, community care and palliative care services 61

Some common triggers that should alert the MDT to the need for further investigation and review may be:

- deterioration despite medical treatment
- development of new clinical problems
- poor or incomplete response to medical treatment
- advanced age with increasing frailty, reduced cognition, functional status and mobility, and increasing difficulty with activities of daily living
- clear signs that the patient is in physical, psychological or emotional distress
- clinical determination that the patient will not benefit from changes to their treatment
- multiple readmissions to hospital or unplanned prolonged stays in hospital.

**Referral to palliative care**

Some patients may already have ongoing involvement of palliative care, particularly those on RSC pathway. However, others including transplant recipients and those on dialysis may experience sudden decline in health and therefore engagement of the palliative care team may only occur when end of life is imminent.
Referral to palliative care may include: nursing; pastoral care; palliative medicine; inpatient palliative care bed access as required; social work; and bereavement counselling, along with general practitioner and renal services engagement. There needs to be consideration of appropriate place of care and preferred place of death. If this is to be at home or in the community, involvement of other services such as home and community-based care, specialist community palliative care workers and community nursing may be required.62

Further information

- Palliative Care Victoria
- Department of Health and Human Services, Palliative Care Program
- The International Collaborative for Best Care for the Dying Person, International Interim Model Integrated Care Pathway (ICP) Documentation: Supporting Care in the Last Hours or Days of Life63

Fact: Ten key elements for best care for the dying

Internationally, there are ten recognised key elements for best care for the dying.60

1. Recognition that the patient is in the last hours or days of life should be made by the multidisciplinary team and documented by the senior doctor responsible for the patient’s care.

2. Communication of the recognition of dying should be shared with the patient where possible, and deemed appropriate and with the relative or carer or advocate.

3. The patient and relative or carer or advocate should have the opportunity to discuss their wishes, feelings, faith, beliefs and values.

4. Anticipatory prescribing for symptoms of pain, excessive respiratory secretions, agitation, nausea and vomiting, and dyspnoea should be in place.

5. All clinical interventions are reviewed in the best interest of the individual patient.

6. There should be a review of hydration needs, including the commencement, continuation or cessation of clinically assisted (artificial) hydration.

7. There should be a review of nutritional needs including the continuation or cessation of clinically assisted (artificial) nutrition.

8. There should be a full discussion of the plan of care with the patient where possible, and deemed appropriate and with the relative or carer or advocate.

9. There should be regular reassessments of the patient at least every four hours.

10. Care of the patient and relative or carer or advocate immediately after death is dignified and respectful.

Patient concerns

Patients and their families will have a range of concerns as the end of life becomes increasingly imminent. Patients may be concerned about their self-perceived level of burden and what will happen to family members when they die. Patients and carers may be concerned about such things as dignity, respect, flexibility and control. In addition, studies have shown that concerns around equity of access to services, assistance and support have been shown to be of issue.64

Further information

- Victorian Department of Health and Human Services Palliative Care Program
Person-centred care and shared decision making

The patient needs to know they are imminently dying and that they will be supported in their dying, and that their family and carers will be supported into their bereavement. If the person has decided to withdraw from dialysis, this must be an informed decision, and assessment should be undertaken to ensure that they are not depressed.

Quality end-of-life care should include:
- engagement of the person and their family and carers
- communication and support for the person and their family and carers
- optimal symptom management
- end-of-life care plan, including preferred location of care – inpatient – renal; renal with specialist palliative care; specialist palliative care or community palliative care or GP
- ACP or revisit of current advance care plan especially around re-clarification of resuscitation status and management of deterioration, enacting of MEPOA

To facilitate enhanced patient care and support, the MDT should consider seeking additional expertise from:
- pain specialist
- pastoral carer or spiritual advisor
- bereavement counsellor
- therapist (for example, music or art).

The team might also recommend accessing:
- home and community-based care
- specialist community palliative care workers
- community nursing.

Consideration of an appropriate place of care and preferred place of death is essential, but noting that this can change, so ongoing review by the MDT is essential.

Further information
- Refer patients and carers to Palliative Care Australia.
- A list of inpatient, community and specialist RSC services is available from the Department of Health and Human Services Palliative Care website.
- Principles for good end-of-life care.

Source: Adapted from literature
Screening and assessment

For many patients, carers and families, the focus of end-of-life care should be on maintaining comfort and reassurance that the person will die with their goals and wishes understood and where possible met, and their physical, psychological and spiritual needs met. Active medical treatment remains an important component of overall care and management of the patient, but should be focused on achieving these aims and objectives and enabling the patient to die with dignity.

Regular and routine screening and assessments of people at the end of life is required to identify their needs. If admitted to palliative care services, other palliative care assessments may be undertaken to identify needs and assist in the development of an end-of-life plan, which may include:

- distress thermometer
- **Palliative Care Outcome Collaboration** (PCOC), which uses:
  - palliative care phase
  - Resource Utilisation Groups (RUGS) activities of daily living
  - Australian-modified Karnofsky performance scale (AKPS)
  - palliative care problem severity score
  - symptom assessment scale.
- Good patient care ensures that:
  - all people with CKD who are imminently dying have an end-of-life care plan which has been developed in collaboration with them (if they are able) and their families/carers and based on appropriate assessment
  - unnecessary medical treatment, tests and medications are avoided
  - the patient’s, substitute decision maker, carer or family member are empowered to request a second opinion or a review of the care plan at any time.

The VRCN, in collaboration with the renal sector, is currently undertaking a project that aims to identify a process for comprehensive patient assessment for Victorians with Stages 4 and 5 CKD. The final outcome of this project is expected to be available by early 2017.

Information and education

Key to achieving good end-of-life care, patients and families/carers need to be educated, informed and accepting of the needs of people approaching end of life. For some people this may mean referral to palliative care services. It is therefore important that renal health professionals are knowledgeable about:

- what services inpatient and community palliative care can provide
- how referrals can be made to inpatient and community palliative care services.

It is important to presume that every adult patient has the capacity to make decisions about their care and treatment, including end-of-life care.

Clinicians and other professionals should not assume that a patient lacks capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including mental illness), beliefs, apparent inability to communicate, or because they make a decision that others disagree with or consider unwise.

It is important that all patients with CKD are encouraged to have an ACP to ensure that the clinical team and the patient’s family are able to make decisions in line with the patient’s wishes, should they not be in a position to do so themselves.
Patients and their families that are approaching end of life must be treated with compassion, dignity and respect. This includes the provision of information about what to expect over the coming days/weeks, as well as addressing individual patient needs.

Nephrologists and other key members of the care team need to be confident that they have the skills to recognise and appropriate manage patients who are imminently dying. This includes knowing when to refer to palliative care and/or when to implement advance care directives.

Further information
- Advance Care Planning Australia
- RACGP Practice information and tools for ACP

### Integrated care

End-of-life care should be provided by an integrated MDT relevant to the needs of the individual person and their family/carers.

The clinician leading the MDT and who has prime responsibility in coordinating patient care must be clearly identified.

The roles and responsibilities of each member of the MDT must be clearly identified and understood by all involved in the patient’s care, including the patient’s, their carers and their family. Figure 7 includes the most common members of a good MDT.

Depending on the location of death, care may be provided by primary care (GP and community support services), nephrologists, renal nurses, nurse practitioners, palliative care clinicians, allied health and pastoral care.

Patients approaching end of life must continue to be medically managed, with a particular focus on minimising symptom burden.

For patients unable to speak for themselves, their substitute decision maker must be clearly identified. Depending on individual patient needs, other healthcare professionals may need to be included in the MDT.

### Clinicians and patients and their carers and families might engage in end-of-life care discussions:

- when the patient or their carers or family expresses an interest in discussing end-of-life care
- when the patient has an uncertain prognosis and is likely to die in the short term
- if unexpected, significant deterioration in condition occurs
- if a sudden life-threatening event occurs
- as part of routine education and ACP conversations.
Access and equity

- All people who are imminently dying should have access to an appropriate level of care and support.
- Health services may need to use a variety of approaches in accessing and providing care and support, which may include telehealth for those who do not have access to specialist palliative care within their local area.
- Consideration must also be given to the patient’s cultural or religious beliefs, as well as other issues that may impact a person’s ability to access appropriate end-of-life care.
- Health providers to ensure (as far as possible) that all people with CKD who are imminently dying have the opportunity to die where they wish with the support and care they need.
- Renal services should have clearly defined processes in place for timely access to the assistance with end-of-life care for their patients. This should include rapid access to specialist palliative care advice 24 hours a day, seven days a week.

Further information

- National Palliative Care Research Centre
- Care Search Palliative Care Knowledge Network
Palliative care services in Victoria

Victorian palliative care services include the following:

1. **Inpatient palliative care services.**
   These provide care to patients who require complex symptom and pain management or end-of-life care. Inpatient palliative care is provided within designated palliative care beds and by specialist consultancy teams. Palliative care beds in Victoria are located within public hospitals, as part of purpose-built subacute units or services or as stand-alone services.

2. **Palliative care consultancy services.**
   These are funded in all public metropolitan and regional health services. Consultancy services provide advice and support to treating teams in hospitals and in the community. Consultancy services also provide direct clinical care, assessment and advice for clients and carers with complex needs. This means the treating team can maintain care of the person with a life-threatening illness and address their pain, symptoms and psychological, social and spiritual concerns. Consultancy services work across acute and subacute services and have an increasing presence in outpatient clinics. Consultancy services assist in coordinating discharge planning with community palliative care services where patients wish to be cared for and/or die at home and transition to other specialist inpatient, subacute or residential locations.

3. **Community palliative care services.**
   These provide holistic care based on assessment of client needs and those of their family and carers. Support can include nursing care, allied health, respite and practical support, as well as information, equipment, medications and access to medical review and assessment in peoples’ homes.

**Suggestions for implementation**

1. Ensure that all people with CKD who are imminently dying have an end-of-life care plan which has been developed in collaboration with them (if they are able) and their families/carers.

2. Ensure that all people with CKD who are imminently dying have the opportunity to die where they wish with the support and care they need.

3. Ensure that families/carers of people with CKD who are at the end of life or who have died have access to bereavement services.

4. There should be effective referral and communication pathways between renal health professionals, general practitioners and palliative care teams in order to provide streamlined care and effective use of health and human resources.

5. Advance care planning should be offered to all people with CKD.

6. A national project/research to evaluate which delivery model(s) of palliative care for someone with CKD are most cost and resource effective and enhance the person’s quality of life.


63. Marie Curie Palliative Care Insitutue Liverpool (MCPCIL). The International Collaborative for Best Care for the Dying Person. International Interim Model Integrated Care Pathway (ICP) Documentation: Supporting Care in the Last Hours or Days of Life. 2014 (May).


Appendix A: Sustainability, technology and innovation

Service sustainability
A key priority for the delivery of future renal services in Victoria is to develop a flexible, accessible and sustainable service system for patients. To do this, a balance needs to be found between providing care to patients as close to home as possible, while still maintaining centres of excellence to ensure the best possible management of patients with complex care needs, appropriate workforce training and development, ongoing clinical research and a critical mass of patients.

Health services need to ensure that their services meets patient needs and use resources effectively and sustainably. Opportunities for service enhancement through the development of more efficient service and workforce models, better use of new technologies and information and communication technologies (ICT) and a greater focus on minimising the environmental footprint of renal services will assist in the development of a more sustainable and productive renal service system.

Continued development of the renal service system will be undertaken as part of a broader Department of Health and Human Services reform agenda. This will incorporate a major review of statewide renal services (including a funding review) and managed in a planned and coordinated manner, by the department’s Renal Health program area in collaboration with the VRCN and the Organ and Tissue Donation program (which also provides advice on organ transplantation). There is an expectation that services will work together to provide the best possible service system for all Victorians with CKD. Opportunities to enhance the way that service work together may be explored in the future, including a more geographical and regionalised approach to service planning.

Information and communication technology (ICT) and new technology
Health services are increasingly implementing new and improved ICT solutions in order to improve clinical care, service planning, performance monitoring and patient management. Although the fully digital hospital and patient-held electronic medical record may still be some years away, ICT is making significant inroads and providing considerable scope and opportunity for better engagement with patients and other service providers, as well as opportunities to streamline and coordinate care delivery.

New technologies and advancements in medical science including clinical practice, medical equipment, drug therapies, surgical procedures and other innovations (such as gene therapy, improved understanding of genetics and DNA mapping), as well as other emerging technologies, will change the future care and treatment of people with CKD.

In addition to new clinical devices and therapies, ICT is also providing significant opportunities to enhance flexibility and accessibility through the use of smartphones or iPad apps to support patient care. In the future, this could include a broad range of applications from basic information and education, though to patient ‘passports’ for collating all patient information and clinical decision support for clinical staff.

Horizon scanning and monitoring the introduction of new health technologies will assist in the prioritisation and allocation of resources to ensure maximum utilisation of resources, particularly those that will impact long-term planning and future health issues.
Telehealth

Telehealth refers to healthcare delivery, or related processes (such as education), when some of the stakeholders (for example, clinicians, patients, family and so on) are separated by distance and information and communications technologies are used to overcome that distance. Telehealth can be a cost effective, real-time and convenient alternative to the more traditional face-to-face way of providing healthcare, professional advice and education. It can help to remove many of the barriers currently experienced by health consumers and professionals (such as distance, time and cost), which can prevent or delay the delivery of timely and appropriate healthcare services and educational support.

Telehealth potentially offers the person with CKD greater time convenience and general practitioners (GPs) and specialist renal services the potential to promote significant efficiencies in relation to improved care, better disease management and reduced costs. There is also an opportunity to provide greater level of staff support, education and training – especially for staff working in small rural satellites services.

Currently, e-consultations, remote monitoring (telemetry monitoring) are being used to provide some patient-level care; however, technology is available to provide a far greater scope of practice, such as: remotely monitoring variables such as physiological data, vital signs, medical emergencies (for example, alarms or alerts falls or other major changes in health condition), patient treatments (for example, dialysis treatments) and medication management. Telehealth also provides opportunities to deliver a far greater range of support services, including some allied health, patient education and patient assessments.

Bright idea: Home dialysis utilising telehealth guidance (HUG) project

Western Health

Western Health’s Department of Nephrology is using innovative telehealth solutions to provide greater levels of support and monitoring, enabling more patients to undertake home dialysis. The HUG system is an integrated approach to in-home dialysis management, supported by video conferencing, which allows the care team including practice nurses to respond to changes in the patient’s condition and treat accordingly.

The trial is collecting weight and blood pressure data for each patient through remote monitoring that is blue-toothed through a secure portal, where the renal nurse is able to check on each patient’s data each day. Video conferencing is also being utilised so that nurses can assist patients with correct needling and review exit sites for infection or inflammation.

In addition, the renal dietitian can also conduct video conferences with patients in their own homes, remotely looking through their pantries and fridges and discussing foods with them.

Since its introduction, the number of new patients choosing in-home dialysis has increased from an incidence of 18 per cent in 2013 to 43 per cent in 2015. Early results indicate that by introducing telehealth, the patient’s care team can be more involved in education, helping the patient to better manage their condition, without the traditional impact on staff time and resources.
New technologies
It is essential that the service model adopted across the state is not only best practice, high quality care, but that it is sustainable and viable into the future. Opportunities for the renal service system include proactive investment in: technology, research and implementation of evidence-based practices, improvements in productivity, and continuous improvement initiatives. Over the coming years, advancements in technology will result in smaller more portable dialysis machines, and hopefully, in the not-too-distant future, new technologies such as the wearable artificial kidney (WAK).

In recent years, there have been several technological innovations in the field of transplantation. For example, with the proportion of potential deceased donors compared to the numbers of patients on the waiting list is increasing, and therefore opportunities to improve the numbers of transplantations each year have focused on expanding the available donor pool through strategies and interventions targeted at increasing the numbers of available organs.

Some of these strategies are:
• living paired donation transplants
• combined kidney and pancreas transplants
• extended criteria donation (that is, marginal kidneys)
• incompatible blood or tissue type transplant (for example, ABO incompatible transplants)
• highly sensitised patients
• kidney perfusion machines to improve graft survival and potentially expand criteria for donation.

Further information
• Victorian Department of Health and Human Services Telehealth Program
• Medicare Australia Telehealth Program and Eligibility
• Australian Government Organ and Tissue Authority

Data collection and performance monitoring
All renal services in Australia and New Zealand regularly contribute to the Australia and New Zealand Dialysis and Transplant Association (ANZDATA) and Australia and New Zealand Organ Donation (ANZOD) registries of kidney disease. Consequently, there is now a considerable body of longitudinal data regarding dialysis and transplantation trends and aetiologies. In addition, Victoria collects data via several patient level databases, the Victorian Renal Register and against several key performance indicators (KPIs).

Despite this extensive data collection, there are several gaps that have been highlighted as part of the development of the RICP; in particular, the lack of data available around early CKD and patients with CKD or are receiving RSC.

Funding
The department provides funding (both direct and indirect) to support renal transplantation and dialysis treatments. Currently, there is no specific funding stream for RSC, although patients are eligible to access funded programs such as palliative care, Home and Community Care (HACC), and the Health Independence Program (HIP).

With respect to renal transplantation, the department funds costs associated with transporting the organ retrieval team to the donor’s hospital, the costs of surgery at the donor’s hospital and the costs of transporting the team with the donated organs back to the transplant hospital, as well as funding for costs associated with tissue typing. The transplant surgical procedure is funded through activity-based funding (WIES).

Funding for public dialysis services comprises two streams, being:
• a WIES payment paid directly to the dialysis provider to cover dialysis service provision, including consumables and coordination costs
• a funding allocation to specialist services to fund non-admitted (outpatient) clinical consultations.

Home dialysis is funded as a block capitation grant to the patient’s parent hospital, and includes annual allowances to be paid to patients to help offset the cost of additional power and water usage.

Patients can also access care from private nephrologists, payable through the Medicare Benefits Schedule (MBS) and private satellite dialysis services, with the costs associated with this payable by the patient (these may be recoverable through private health insurance rebates).

Patients should be able to access renal services, including their preferred choice of treatment (where clinically appropriate) irrespective of their geographic location, financial status or cultural and linguistic background. Funding for the treatment of CKD and its associated treatments should not impact renal services in providing high quality, timely and appropriate healthcare.

**Workforce**

The implementation of the RICP requires that there is a long-term plan to identify future workforce needs and that there is a pool of appropriately skilled and experienced staff. The provision of renal services for people with CKD relies heavily on a strong multidisciplinary team with close working relationships between physicians, surgeons, specialist renal nursing staff, dieticians, pharmacists, social workers and other allied health, as well as other supporting services such as radiology and pharmacy. In addition, it also involves a workforce that spans the primary, secondary and tertiary health sectors as well as the public and private healthcare systems.

By providing support and guidance around the provision of best practice care for people with CKD, the RICP provides opportunities for the renal team to enhance the way they work both within the renal services and more broadly with other service providers. For example, this may involve working more collaboratively with other specialist clinical services such as primary health, chronic disease management services, diabetes services, cardiovascular services and palliative care services.

The need for flexibility and new ways of working to make the best use of skills and knowledge is required in order to meet the changing needs of patients, carers and families, and to ensure that Victorian renal services reflect current best practice evidence-based clinical care. This project provides the opportunity to either expand existing roles, or create new roles in order to provide renal services. For example, continued expansion of the advance practice nurse and nurse practitioner roles, more opportunities for enrolled nurses (ENs), along with new nursing roles that better support home based patients, or utilising other community-based nursing services and models.

Within the primary care sector, there are opportunities to up-skill GPs and general practice nursing staff to better understand the importance of early detection and treatment of CKD in their patient cohort.

The importance of allied health services for renal patients is well recognised. Dietetics and social work are generally regarded as essential in order to maintain health and wellbeing of patients with CKD. However, it is also been found that other allied health services (such as occupational therapy, physiotherapy, psychology and podiatry), as well as clinical support services (such as pharmacy) can provide significant benefits to people with advanced CKD in terms of their general physical and mental functioning. However,
these specialists are not always accessible to patients with CKD.

A key workforce issue is the difficulties related to determining an appropriate mix of medical, nursing and allied health staff needed to support a CKD service. Comprehensive assessment of patient needs will assist in the determination of more specific workforce requirements within the renal service sector, along with improved data collection and data analysis.

High quality education of the renal workforce is essential to good patient care. To achieve this it is important that all staff can access educational activities irrespective of their work location or other work/life commitments.

Research and teaching

Participation in research is an important part of the provision of high quality care to patients with CKD. Clinical trials and other research strategies are generally used to test the safety and effectiveness of drugs and devices and can contribute important information about the benefits and safety of existing medications and therapies, as well as testing potentially new therapies. All suitable patients should be given the opportunity to participate in clinical trials, because they have often been shown to provide participants with personal advantages, such as improved clinical outcomes or better HRQoL.

Clinical research can provide clinicians and patients with reliable information for choosing between alternative treatments as well providing a valuable contribution to the health and safety of others with CKD, both now and into the future. Accordingly, there will be a strong research component across all renal services within Victoria supporting and informing the delivery of clinical services. This will include:

• identification of opportunities to build on existing relationships with universities
• exploring opportunities for research within the nursing and allied health sectors, particularly focusing on developing an evidence-base body of knowledge to support future practice and approaches to the care of people with CKD
• building on existing relationships with clinical renal networks including Australian Kidney Trials Network (AKTN) and other organisations such as the NHMRC
• ongoing research to inform protocols and establish a growing body of evidence on best practice.

A recent workshop hosted by Kidney Health Australia (KHA) identified several research priorities from a consumer perspective and developed a prioritised list of 20 research questions encompassing CKD, transplantation and dialysis. It is noted that many of the questions focus on behaviour modification, decision making, HRQoL and education.

Environmental sustainability

Renal services are known as high users of water and power and producers of waste. The large volumes of water utilised by the dialysis process, along with the many kilograms of waste such as tubing, wrappings, plastic containers and other assorted consumables contribute to the generation of greenhouse gas emissions. In addition, patients may travel many kilometres three times a week (156 times a year), driving to satellite dialysis centres, thus generating many carbon miles. Dialysis equipment also requires considerable consumption of electricity over the course of a year.

Adopting environmentally sustainable practices has the potential to not only deliver operational cost savings to health services and patients, but also provides many short- and long-term benefits to the broader community.
The VRCN recognises that good healthcare is not just about providing good clinical care; it is also about protecting the health of our planet for future generations. Responding to concerns about the environmental impact of providing renal services, the VRCN has recently formed the Environmental Sustainability Special Interest Group (ESSIG).

The ESSIG is the first statewide group specifically focusing on improving sustainability practices in renal facilities. The ESSIG aims to assist renal services to reduce the environmental impact of providing renal care, while maintaining clinical best practice and maintaining or improving economic viability. The ESSIG is exploring opportunities to help renal services target specific issues that may impact patient HRQoL, service efficiencies, waste reduction and financial savings. Renal services are encouraged to explore opportunities to develop and implement environmentally sustainability practices.

**Further information**
- [Department of Health and Human Services environmental sustainability in dialysis units](#)
- [Green dialysis](#)

---

**Research priorities in CKD**

- Patients, carers and clinicians came together in February 2014 to explore research priorities in CKD.
- 83 research questions generated
- A ‘Top 20’ list was compiled.
- Patient research dialysis priorities focussed on:
  - lifestyle (e.g. exercise, diet & nutrition, maintaining work while on HD)
  - improving psychological health
  - patient education, and
  - new technology

**One patient’s perspective**

‘A cure for my form of kidney disease would be an improvement. Research and development in tissue engineering so that replacement kidneys could be grown that are compatible with my immune system (so that I don’t have to take immuno-suppressants with a transplant)’.

(NSHD, Male, Metro, 60-69 years)
Appendix B: Five Rs of good patient care

A supportive approach to the provision of good patient care for people with CKD aligns with the five Rs of renal care (see Figure 8):

- **Risk**: Understanding and addressing the factors that lead people to develop CKD, which is increasingly a consequence of modifiable lifestyle factors as well as genetic predisposition. Public health surveillance to increase awareness of kidney disease, as well as greater support and education for general practitioners (GPs) to provide targeted assessments will provide long-term benefits to the broader population.

- **Recognition**: By recognising CKD early, the primary cause of the disease can be diagnosed and appropriate interventions instigated, including addressing comorbidities (particularly cardiovascular disease and diabetes) and monitoring disease progression.

- **Response**: For those whose kidney function continues to decline despite early intervention, timely referral to specialist renal services may be required. Patient care becomes more individualised by addressing barriers to change, targeted medication management, supported by a comprehensive program of information and education regarding CKD and options for future treatment.

- **Renal support**: Patients choosing transplantation or dialysis treatments require timely work-up and preparation to facilitate a planned start to therapy that best meets the patient’s personal goals and objectives. All patients choosing RSC will receive ongoing treatment through a RSC program. Patients changing treatment modalities will be able to access appropriate support and education that links back into the CKD pathway. For those withdrawing from treatment high quality end-of-life care based on the patient’s values and beliefs is essential.

- **Rehabilitation**: The primary purpose of RRT must be to enhance HRQoL and to enable people with CKD Stage 5 to live as normal a life as possible. Regular screening and assessment to enable identification of issues such as cognitive or functional decline, mental health problems, nutritional issues or other health or non-health related problems (for example, financial, relationship or work/study stresses). Renal services should develop a proactive approach to rehabilitative care based on the concept of ‘prehabilitation’ prior to commencement of treatment as well as rehabilitation as an ongoing intervention.
Figure 8: Five Rs of renal care

1. **Risk**
   - Genetics
   - Risk assessment
   - Public health
   - Primary care
   - Electronic systems

2. **Recognition**
   - Target those at high risk
   - Education and prevention
   - Primary cause/s
   - Comorbidities
   - Severity
   - CKD progression
   - Lifestyle modification
   - Risk scores
   - Address barriers to change
   - Medication management
   - Control blood pressure
   - Timely education and decision support
   - Chronic disease management

3. **Response**
   - Nephrotoxins
   - Referral
   - Reversible factors
   - Risk scores
   - Address barriers to change
   - Medication management
   - Control blood pressure
   - Timely education and decision support
   - Chronic disease management

4. **Renal Support**
   - Renal replacement therapy
   - Preparation
   - Planned start with access in place
   - Pre-emptive transplant or timely NOMS listing
   - Home for dialysis
   - Renal supportive care for non-dialytic therapy
   - Planned and considered
   - Patient’s beliefs and values known
   - Advance care planning
   - Good end-of-life care
   - Regular screening and assessment
   - Nutrition management
   - Education and information
   - Best quality of life
   - Good physical and mental health
   - Effective symptom management

5. **Rehabilitation**
   - Recovery model of care
   - Follow up
   - Regular screening and assessment
   - Nutrition management
   - Education and information
   - Best quality of life
   - Good physical and mental health
   - Effective symptom management
Appendix C: Populations with special needs

Culturally and linguistically diverse (CALD) populations

Victoria is a diverse community which includes people from many cultures, many of whom do not have a high level of written or verbal English proficiency. Consequently, many people with CKD have issues in communication and understanding due to cultural and language differences which may impact their clinical decisions and health outcomes. Studies have suggested that CALD people often experience inequitable access to health services as a consequence of obstacles in communication due to language and cultural issues, and may then have issues around such things as medication management, self-care, decision making, and so forth.

Ensuring that health services incorporate strategies to address language or cultural issues is essential to good patient care. Strategies should be developed that meets individual patient needs, but may include:

- an increased use of interpreters in consultations
- longer consultation times
- the use of health professional staff who speak the same language
- information regarding clinical information, medications or medical procedures provided in the participants’ language.

Aboriginal renal health

Aboriginal and Torres Strait Islander peoples make up approximately two per cent of the Australian population; however, they constitute almost ten per cent of people commencing dialysis for Stage 5 CKD. A further issue for Aboriginal Australians is the low rate of transplantation. For example, in 2011 only 3.4 per cent of recipients were of Aboriginal or Torres Strait Islander identification, compared to 79.6 per cent Caucasians and 11.8 per cent of Asian descent.

Ensuring improvements to health outcomes for Aboriginal and Torres Strait Islander people is essential to basic human dignity, and the service delivery model for renal services must be accessible and culturally appropriate to meet the specific needs of the Aboriginal and Torres Strait Islander population.

Older people with CKD

‘Elderly patients comprise the fastest growing population initiating dialysis and also experience the worst outcomes, including increased mortality, loss of functional status, and impaired quality of life.’ Planning and delivering appropriate care for older people with CKD presents several challenges, such as a rapid deterioration in health and limited ability to self-care. The older person is much less likely to be a suitable candidate for a kidney transplant, leaving dialysis or RSC as the only potential medium- to longer-term treatment options.

Improved communication between the fields of nephrology and geriatrics is required to facilitate the delivery of best practice care, which takes into account physiological age, complex comorbidities, risk of adverse events and drug interactions, as well as implications of cognitive impairment on suitability of treatment and consent.

Assessment should be used to determine life expectancy and treatment tolerance, as well as identifying conditions that might interfere with treatment, including:

- functional status
- comorbidity
- presence of geriatric syndromes
- nutrition
- polypharmacy
- cognition
- emotional wellbeing
- social supports.
As for all patients, management of CKD in many elderly patients should be individualised rather than disease focused, given the common interplay of complex comorbidities together with variability in functional status, life expectancy and health priorities. The nephrologist and other members of the clinical team need to consider the potential benefits of dialysis versus a supportive approach to symptom management, particularly if the older person has multiple comorbidities and is likely not to achieve any real benefits from a treatment as invasive as dialysis.

The older person’s general practitioner will ideally screen for evidence of kidney disease and manage according to the relevant guidelines, including specialist referral where indicated.

People with a disability

Disability can involve impairment or loss of function and may include physical, intellectual or sensory disability, acquired brain injury, neurological impairment or mental health issues. The severity of the disability will differ between individuals. People with a disability are more likely to have health problems and experience social or economic disadvantage than the general population.

In the case of people with CKD, the disability may have been present prior to the onset of the disease or acquired after established CKD. The disability may or may not be related to the person’s kidney disease; however, the issues associated with CKD may exacerbate existing disabilities.

It is essential that renal services appropriately support patients with any disability, such as accommodating difficulties such as communication issues, cognitive impairment, travel or mobility constraints, or mental health issues. It is important that renal services recognise, and support the additional burdens that people with CKD and who also have disability by being aware and responsive to the problems that these patients may be facing.

In caring for people with a disability renal services should:

- ensure that education and information is delivered in a manner and format that can be understood by a person with hearing, visual, cognitive or other impairment
- ensure that all assessments take account of the disadvantages that impact people with a disability
- consider how best to support people needing to access renal services, such as transportation to and from satellite dialysis or outpatient appointments; additional time for consultations and appointments; considering the need for additional support people to assist with consultations or treatments; and ensure that renal services staff are appropriately trained and supported to manage patients with a disability. This last point is particularly relevant for staff of satellite units who may need to manage a patient with a disability several times a week for many years.

It is also essential that people with CKD are capable of making informed consent for treatments for their disease, or failing that, are represented by a person with decision-making rights.

Adolescents and young adults

Adolescents with kidney disease are another particularly vulnerable group. In young people CKD typically occurs as a consequence of ‘fixed’ congenital disease, rather than the behavioural or biomedical factors that are more likely to impact the adult population. Chronic childhood illness may interfere with normal maturation, and sub-optimally treated childhood uraemia can impair growth and cognitive development.

In addition, many young people with renal disease may have delayed physiological and psychosocial development, academic disadvantage and diminished self-esteem. While many young people are able to obtain a kidney transplant, they still need to cope with a life-time regime of immunosuppressant drugs and related side effects.
At some point these younger patients will need to transition to an adult renal service from a paediatric service for their ongoing care and treatment. The transfer from a paediatric to an adult renal unit can be difficult for the young person and their family, especially for those requiring dialysis. Paediatric care is typically more nurturing and one on one. In contrast, the adult environment can be much more of a business-like and busy environment. The issues and concerns of the young adult are also quite different from the majority of older people with advanced CKD.

The timing of transfer to an adult renal unit should therefore be planned well ahead and agreed by the adolescent and their parents, as well as by members of the paediatric and adult renal medical teams.

An additional issue might be for parents of the young adult who, up until the point of transition, have been deeply involved in decisions regarding the care and treatment of their child. Clinicians working predominantly with older adults may be unaccustomed to dealing with parents of patients who also may be struggling with their changing role and could consider them overly interfering and intrusive.

Adult renal services caring for adolescents and young adults should:

- have a clearly understood process for transition of care from the paediatric to adult renal service
- ensure access to expert paediatric health professionals who possess knowledge specific to the biomedical and psychosocial needs of the younger person
- understand the biology and current management of the disease in the adolescent and young adult age group
- engage in proactive discussions about the patient’s psychosocial needs
- provide treatment in an environment appropriate to the needs of the younger person.
## Appendix D: Elements of a successful education program

<table>
<thead>
<tr>
<th>Key elements</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Commencement</strong></td>
<td>Commence early in the course of the patients CKD pathway (eGFR less than 30 mL/min/1.73 m²), or whose kidneys are likely to fail within 12 months. Also involve late referrals including those who have recently started dialysis with no prior nephrology care</td>
</tr>
<tr>
<td><strong>Program leader</strong></td>
<td>Appropriately skilled CKD nurse educator, supported by a dietician and social worker and other members of the MDT as required</td>
</tr>
<tr>
<td><strong>Target audience</strong></td>
<td>Patients and their families/carers</td>
</tr>
<tr>
<td><strong>Setting/format</strong></td>
<td>One–on–one or in a group setting. Consider telehealth for patients unable to attend in person.</td>
</tr>
<tr>
<td><strong>Content</strong></td>
<td>Comprehensive written and verbal discussion of CKD including:</td>
</tr>
<tr>
<td></td>
<td>• slowing or reversing loss of kidney function</td>
</tr>
<tr>
<td></td>
<td>• importance of preserving veins for future dialysis access</td>
</tr>
<tr>
<td></td>
<td>• kidney transplantation, including living and deceased donor options</td>
</tr>
<tr>
<td></td>
<td>• dialysis treatment options, including PD and HD, home dialysis</td>
</tr>
<tr>
<td></td>
<td>• RSC and what that means in the context of no other RRTs</td>
</tr>
<tr>
<td></td>
<td>• impact of the treatments on lifestyle, prognosis, QoL, etc.</td>
</tr>
<tr>
<td></td>
<td>• importance of advance care planning</td>
</tr>
<tr>
<td></td>
<td>• end-of-life care.</td>
</tr>
<tr>
<td><strong>Frequency</strong></td>
<td>Should be ongoing, but ramped up at key decision milestones such as: prior to dialysis or transplantation or changes in clinical or psychosocial circumstances.</td>
</tr>
<tr>
<td></td>
<td>Ideally patients will receive between three and six formal education sessions relevant to assist with choice of treatment as this will help avoid information overload and allow time to patients and their families to consider the information they have received and to come back with questions regarding that information.</td>
</tr>
<tr>
<td></td>
<td>Patients changing treatment streams should receive further education.</td>
</tr>
<tr>
<td><strong>Other resources</strong></td>
<td>Involvement of current patients including transplant recipients, those on dialysis (both home and centre-based) and, if possible, patients on a RSC pathway is encouraged.</td>
</tr>
<tr>
<td></td>
<td>Tours of dialysis facilities for patients considering satellite dialysis.</td>
</tr>
<tr>
<td></td>
<td>Advice regarding how to access good quality online resources, encourage linkages with consumer and peer support organisations.</td>
</tr>
<tr>
<td><strong>Decision support</strong></td>
<td>Help patients to consider the treatment option that best suits their lifestyle, beliefs and values and is likely to provide the best HRQoL for themselves and their family.</td>
</tr>
</tbody>
</table>
## Table 3: Pathology schedule

<table>
<thead>
<tr>
<th>Test</th>
<th>Jan</th>
<th>Feb</th>
<th>Mar</th>
<th>Apr</th>
<th>May</th>
<th>Jun</th>
<th>Jul</th>
<th>Aug</th>
<th>Sep</th>
<th>Oct</th>
<th>Nov</th>
<th>Dec</th>
</tr>
</thead>
<tbody>
<tr>
<td>U&amp;E (inc HCO$_3^-$, Cl$^-$), CRP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FBE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alb, Ca$^{2+}$, PO$_4$, ALP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iron Studies (Fe, transferrin, TSAT, ferritin)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CRP</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>URR</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PTH</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LFT</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TG, LDH, HDL Chol, Glucose</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vitamin B$^{12}$, Folate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Magnesium</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis B S Ag, S Ab &amp; C Ab</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis C</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HbA1c (Diabetics only)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sera for tissue typing (transplant list patients only)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Further information about the HIP program is available on the Department of Health and Human Service's HIP website.

### Table 4: Health independence program contact information

<table>
<thead>
<tr>
<th>Metropolitan health services</th>
<th>Referral / access phone number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alfred Health</td>
<td>1800 224 277</td>
</tr>
<tr>
<td>Austin Health</td>
<td>9496 2211</td>
</tr>
<tr>
<td>Eastern Health</td>
<td>9881 1100</td>
</tr>
<tr>
<td>Melbourne Health</td>
<td>8387 2333</td>
</tr>
<tr>
<td>Mercy Werribee</td>
<td>8754 3800 (ask for Intake)</td>
</tr>
<tr>
<td>Monash Health</td>
<td>1300 342 273</td>
</tr>
<tr>
<td>Northern Health</td>
<td>9495 3294</td>
</tr>
<tr>
<td>Peninsula Health</td>
<td>1300 665 781 (ask for access worker)</td>
</tr>
<tr>
<td>Royal Children’s Hospital</td>
<td>9345 5695</td>
</tr>
<tr>
<td>St Vincent’s Health</td>
<td>1300 131 470</td>
</tr>
<tr>
<td>Western Health</td>
<td>8345 1877</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Regional health services</th>
<th>Referral / access phone number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albury Wodonga</td>
<td>02) 6051 7433</td>
</tr>
<tr>
<td>Barwon Health</td>
<td>1300 715 673</td>
</tr>
<tr>
<td>Ballarat Health</td>
<td>5320 6690</td>
</tr>
<tr>
<td>Bendigo Health</td>
<td>5454 7055</td>
</tr>
<tr>
<td>Goulburn Valley Health</td>
<td>1800 222 582</td>
</tr>
<tr>
<td>Latrobe Regional Hospital</td>
<td>5173 8506</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subregional health services</th>
<th>Referral / access phone number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bairnsdale Regional Health Service</td>
<td>5150 3468</td>
</tr>
<tr>
<td>Bass Coast Regional Health</td>
<td>5671 3135</td>
</tr>
<tr>
<td>Central Gippsland Health Service</td>
<td>5143 8155</td>
</tr>
<tr>
<td>Castlemaine Health</td>
<td>5471 1575</td>
</tr>
<tr>
<td>Echuca Regional Health</td>
<td>54855 855</td>
</tr>
<tr>
<td>Mildura Base Hospital (Ramsey Health)</td>
<td>5022 3250</td>
</tr>
<tr>
<td>Northeast Health Wangaratta</td>
<td>5722 5555</td>
</tr>
<tr>
<td>South West Healthcare</td>
<td>Warrnambool 5563 4000</td>
</tr>
<tr>
<td></td>
<td>Camperdown 5557 0900</td>
</tr>
<tr>
<td>Swan Hill District Health</td>
<td>5033 9321</td>
</tr>
<tr>
<td>West Gippsland Healthcare Group</td>
<td>5622 6411</td>
</tr>
<tr>
<td>Western District Health Service</td>
<td>5551 8532</td>
</tr>
<tr>
<td>Wimmera Health Care Group</td>
<td>5381 9022</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Rural health services</th>
<th>Referral / access phone number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benalla and District Memorial Hospital</td>
<td>5761 2200</td>
</tr>
<tr>
<td>Colac Area Health</td>
<td>5232 5206</td>
</tr>
<tr>
<td>East Grampians Health Service</td>
<td>5352 9328</td>
</tr>
<tr>
<td>Maryborough District Health Service</td>
<td>5461 0333 (ask for Intake)</td>
</tr>
<tr>
<td>Portland District Health</td>
<td>5521 0653</td>
</tr>
<tr>
<td>Seymour Health</td>
<td>5735 8050</td>
</tr>
<tr>
<td>Stawell Regional Health</td>
<td>5358 8618</td>
</tr>
</tbody>
</table>
# Appendix G: Acronyms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ANZDATA</td>
<td>Australia and New Zealand Dialysis and Transplant Registry</td>
</tr>
<tr>
<td>ANZSN</td>
<td>Australian and New Zealand Society of Nephrology</td>
</tr>
<tr>
<td>AOMS</td>
<td>Australian Organ Matching Service</td>
</tr>
<tr>
<td>APD</td>
<td>ambulatory peritoneal dialysis</td>
</tr>
<tr>
<td>CALD</td>
<td>culturally and linguistically diverse</td>
</tr>
<tr>
<td>CCF</td>
<td>chronic cardiac failure</td>
</tr>
<tr>
<td>CKD</td>
<td>chronic kidney disease</td>
</tr>
<tr>
<td>CAPD</td>
<td>continuous ambulatory peritoneal dialysis</td>
</tr>
<tr>
<td>CARI</td>
<td>Caring for Australasians with Renal Impairment</td>
</tr>
<tr>
<td>COPD</td>
<td>chronic obstructive pulmonary disease</td>
</tr>
<tr>
<td>CVD</td>
<td>cardiovascular disease</td>
</tr>
<tr>
<td>DATA</td>
<td>Dialysis and Transplant Association</td>
</tr>
<tr>
<td>department</td>
<td>Department of Health and Human Services</td>
</tr>
<tr>
<td>eGFR</td>
<td>estimated glomerular filtration rate</td>
</tr>
<tr>
<td>EMR</td>
<td>electronic medical record</td>
</tr>
<tr>
<td>ESA</td>
<td>erythropoiesis stimulating agent</td>
</tr>
<tr>
<td>ESKD</td>
<td>end-stage kidney disease</td>
</tr>
<tr>
<td>ESSIG</td>
<td>environmental sustainability special interest group</td>
</tr>
<tr>
<td>GP</td>
<td>general practitioner</td>
</tr>
<tr>
<td>HD</td>
<td>haemodialysis</td>
</tr>
<tr>
<td>HHD</td>
<td>home haemodialysis</td>
</tr>
<tr>
<td>HRQoL</td>
<td>health-related quality of life</td>
</tr>
<tr>
<td>KDIGO</td>
<td>Kidney Disease Improving Global Outcomes</td>
</tr>
<tr>
<td>KDOQI</td>
<td>Kidney Disease Outcomes Quality Initiative</td>
</tr>
<tr>
<td>KHA</td>
<td>Kidney Health Australia</td>
</tr>
<tr>
<td>KPI</td>
<td>key performance indicator</td>
</tr>
<tr>
<td>RRT</td>
<td>renal replacement therapy</td>
</tr>
<tr>
<td>NHD</td>
<td>nocturnal haemodialysis</td>
</tr>
<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
</tr>
<tr>
<td>NKF</td>
<td>National Kidney Foundation</td>
</tr>
<tr>
<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
</tr>
<tr>
<td>PD</td>
<td>peritoneal dialysis</td>
</tr>
<tr>
<td>VRCN</td>
<td>Victorian Renal Clinical Network</td>
</tr>
<tr>
<td>RRT</td>
<td>renal replacement therapy</td>
</tr>
<tr>
<td>RSC</td>
<td>renal supportive care</td>
</tr>
<tr>
<td>SHD</td>
<td>satellite haemodialysis</td>
</tr>
<tr>
<td>SNHD</td>
<td>satellite nocturnal haemodialysis</td>
</tr>
<tr>
<td>WAK</td>
<td>wearable artificial kidney</td>
</tr>
</tbody>
</table>
## Appendix H: Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance care planning</td>
<td>Advance care planning is a process of planning for future health and personal care. A person makes their values, beliefs and preferences known so they can guide clinical decision making when and if they are unable to make or communicate their decisions themselves. Advance care planning can be verbal or written.</td>
</tr>
<tr>
<td>ABO blood type</td>
<td>The classification of human blood into four groups: A, B, AB, and O.</td>
</tr>
<tr>
<td>Actual Donor</td>
<td>(i) A consented eligible person from whom the retrieval operation is commenced for the purpose of transplantation (this includes donors who may be deemed medically unsuitable at time of surgery or after removal of organs), and/or (ii) A person from whom at least on organ was recovered for the purpose of transplantation.</td>
</tr>
<tr>
<td>Anti-Rejection drugs (immunosuppressive drugs)</td>
<td>Drugs that are used to prevent and/or treat rejection of a transplanted organ.</td>
</tr>
<tr>
<td>Carer</td>
<td>A person who provides personal care, support and assistance to another. A carer may or may not be a relative of the individual being cared for.</td>
</tr>
<tr>
<td>Chronic kidney disease</td>
<td>All kidney conditions where a person has evidence of kidney damage and/or reduced kidney function, lasting at least three months, regardless of the specific diagnosis of disease or condition causing the disease.</td>
</tr>
<tr>
<td>Diabetes and diabetic nephropathy</td>
<td>The most common cause of CKD Stage 5 can be attributed to diabetes — a chronic condition in which blood sugar levels are too high. Diabetes occurs when the body produces too little or none of the sugar regulating hormone insulin, or cannot use it properly. High blood sugar levels can damage the blood-filtering capillaries in the kidneys.</td>
</tr>
<tr>
<td>Donation after circulatory death (DCD)</td>
<td>Donation, for the purpose of transplantation, occurs following death of a person resulting from the irreversible cessation of circulatory and respiratory function.</td>
</tr>
<tr>
<td>End-of-life care</td>
<td>The care and treatment delivered by health professionals and others that supports a person, their carer and their family of a person that is imminently dying. It also includes the care and support of carers, families and the person’s body after death.</td>
</tr>
<tr>
<td>End-stage kidney disease</td>
<td>End-stage kidney disease is an administrative term in the United States. It indicates that a patient is treated with dialysis or transplantation, which is the condition for payment for healthcare by the Medicare ESRD program. The classification of ESKD does not include patients with kidney failure who are not treated with dialysis and transplantation (for example, RSC). Thus, although the term ESRD provides a simple operational classification of patients according to treatment, it does not precisely define a specific level of kidney function, because this is determined by the level of kidney function.</td>
</tr>
<tr>
<td>Glomerulonephritis</td>
<td>Glomerulonephritis involves inflammation and damage of the filtering units of the kidneys (glomeruli), affecting their ability to filter waste products and excess water from the blood. Chronic glomerulonephritis can be caused by infections, immune diseases, inflammation of the blood vessels or conditions that scar the glomeruli, however often the cause is unknown.</td>
</tr>
<tr>
<td><strong>Haemodialysis (HD)</strong></td>
<td>In haemodialysis, blood is diverted from the body to a dialysis machine, where it is filtered before being returned to the body. This type of dialysis can be done at home, in hospital or in satellite clinics. The machine requires special plumbing and the patient must restrict their travel to places where dialysis facilities are available. In most cases, the patient requires assistance connecting to the machine, and a partner, relative or friend can train to do this for home dialysis patients. During haemodialysis, the patient is usually connected to the machine for about 4–5 hours three times per week, when all their blood passes through the machine about six times. If performed at home, patients may have the option of dialysing more frequently for a shorter period (5–7 times per week for about two hours) or nocturnally (six nights per week for about eight hours). During a haemodialysis session, the patient is unable to move away from the machine, though they can sleep and perform activities such as reading, talking or using a computer.</td>
</tr>
<tr>
<td><strong>Health-related quality of life (HRQoL)</strong></td>
<td>Health-related quality of life (HRQoL) includes domains related to physical, mental, emotional, and social functioning. It focuses on the impact health status has on quality of life of an individual. A related concept of HRQoL is wellbeing, which assesses the positive aspects of a person's life, such as positive emotions and life satisfaction.</td>
</tr>
<tr>
<td><strong>High blood pressure</strong></td>
<td>High blood pressure (hypertension) can damage the blood vessels supplying the kidneys. The walls of these blood vessels become thick and the internal diameter narrowed, leading to reduced blood supply and decreased kidney function. Factors that contribute to high blood pressure include, age, obesity, high alcohol consumption and high dietary salt.</td>
</tr>
<tr>
<td><strong>Incidence</strong></td>
<td>The number of new cases (of an illness, disease or event) occurring during a given period.</td>
</tr>
<tr>
<td><strong>Intended donor</strong></td>
<td>A consented eligible person from whom organ donation for the purpose of transplantation was initiated, but donation did not proceed to the retrieval operation.</td>
</tr>
<tr>
<td><strong>Multidisciplinary team</strong></td>
<td>A multidisciplinary team (MDT) is a team of clinicians representing different disciplines that come together to provide care and treatment to for an individual patient. The MDT is structured to meet the specific needs of the patient based on their illness, other comorbidities, health status and so forth. Effective MDT generally comprises a mix of medical, nursing and allied health staff, as well as the patient and their carer and family.</td>
</tr>
</tbody>
</table>
Multidisciplinary care

Multidisciplinary care (MDC) aims to ensure that members of the MDT can discuss all relevant aspects of a renal patient’s physical and psychosocial needs, along with other factors impacting on the patient’s care. MDC has been shown to improve clinical outcomes for patients, while lowering costs to the sector through fewer unplanned hospitalisations, slower disease progression and patient survival. Effective MDC care ensures:

• improved treatment
• improved team communication and support
• improved coordination of patient care
• reduced service duplication
• increased opportunities for recruitment into clinical trials
• consideration of patients physical and emotional needs.

Patient

The primary recipient of care. In this document, the term ‘patient’ may also refer to the individual, the person or the recipient, depending on the context of the discussion.

Peritoneal dialysis (PD)

In peritoneal dialysis, the abdomen is filled with sterile dialysis solution and the blood is filtered through the peritoneal membrane (which covers the abdominal cavity organs such as the stomach, liver and intestines). The dialysis solution contains a type of sugar (usually glucose or dextrose) which draws the waste products and extra fluid out of the blood, through the peritoneal membrane and into the solution. After a few hours, the used solution, now containing the wastes and extra fluid, is drained out of the body and replaced with fresh solution.

This process is called an exchange, and takes about 30–45 minutes. In between exchanges, the patient is free to continue their usual activities. The patient can either perform peritoneal dialysis during the day (continuous ambulatory peritoneal dialysis), usually three or four times, or automatically at night using a machine for about 8–10 hours while the patient sleeps (automated peritoneal dialysis). Because the necessary equipment is portable, peritoneal dialysis can be performed almost anywhere. The patient does not need to be in a hospital or clinic, and can usually manage the procedure without assistance.

Polycystic kidney Disease (PKD)

A hereditary condition that results in the formation of cysts throughout the kidneys. Patients with PKD often require kidney transplantation.

Pre-emptive transplantation

Pre-emptive kidney transplantation is carried out for patients who are medically suitable before dialysis is needed. A kidney may be used from a living or deceased donor, although a living donor is preferred.

Prevalence

The number or proportion (of cases, instances) present in a population at a given time.

Recipient

A consenting eligible person into whom organs, retrieved for the purpose of transplantation, are received.

Retrieval

The procedure of removing organs or tissue from a donor for the purpose of transplantation.

Transplantation

The transfer of organs or tissue from donor to recipient with the aim of restoring body function(s) of the recipient.
Wait list (WL)  
The list of candidates registered to receive a kidney transplant. When a donor organ becomes available, the matching system generates a new, more specific list of potential recipients based on the criteria defined in that organ’s allocation policy (for example, organ type, geographic local and regional area, genetic compatibility measures, details about the condition of the organ, the candidate’s disease severity, time spent waiting and so on).

Waiting time  
The amount of time a candidate is on the wait list. Waiting times can be influenced by many factors, including:
• blood type (some are rarer than others)
• tissue type
• height and weight of transplant candidate
• size of donated organ
• medical urgency
• time on the waiting list
• the distance between the donor’s hospital and the potential donor organ
• how many donors there are in the local area over a period of time
• the transplant centre’s criteria for accepting organ offers.