

## Kidney Optimal Health Program (KOHP)

### **Kidney Disease Specific information**

St Vincent's Renal Unit treats close to three hundred patients across Victoria for End Stage Kidney Disease (ESKD) on dialysis and a similar number currently for chronic kidney disease but who as yet do not require dialysis. These patients are from across Victoria and Melbourne and see our nephrologists via the public or private service either regional or metropolitan.

St Vincent's patients perform dialysis in their home or attend for in-centre haemodialysis. We have a transplant service, and also care for patients who chose not to have dialysis but have supportive care. The patients have a team of health specialists including; transplant nurse and surgeon, nephrologist, palliative care physician, dietician, social worker, home dialysis specialist nurse and a specialist ward.

Treatment is aimed at slowing the progression of chronic kidney disease and avoiding ESKD and dialysis. For those that require dialysis the aim is to have the patient prepared for treatment before they become unwell. Practically this means the patient has had education about their treatment options (e.g. peritoneal dialysis, home haemodialysis), has decided on one, has had the access surgery performed and is ready to start. The reality is that not all patients start dialysis prepared which can mean a prolonged hospital stay and a slower path to regaining health. Along this pathway very little is established to help patients cope with burden of kidney disease particularly in terms of their mental health.

Here is a summary of kidney disease nationwide and an accurate perspective on the state of play;

[http://kidney.org.au/cms\\_uploads/docs/state-of-the-nation-2015-web.pdf](http://kidney.org.au/cms_uploads/docs/state-of-the-nation-2015-web.pdf)

### **Kidney Optimal Health Background**

As established in the Kidney Health Australia resource (link from the previous paragraph), chronic kidney disease is a serious and growing health problem with enormous impact on social and psychological functioning. Despite high rates of comorbid depression and anxiety in ESKD, and despite disquieting evidence of their potential effects on treatment adherence, quality of life, intimate relationships, level of disability, medical outcomes, survival, and health care costs, very little has been done to prevent or manage these problems. Whether interventions targeted at anxiety and depression have the capacity to reverse such effects in ESKD is at present unknown, but it is clear that studies are urgently needed. The Optimal Health Program (OHP) is an evidence-based psychosocial program that has been used in a range of chronic mental health patient populations to improve outcomes in depression and anxiety. We are hoping this trial will result in the establishment of the Optimal Health Program in the patient's treatment pathway.

## Medical Treatment Options

Patients can take a strategic approach to treating their kidney failure based on maximizing time on each modality. The patient would start on the easiest home dialysis choice, peritoneal dialysis, and transition then to home hemodialysis if necessary and reserve in-centre hemodialysis for when they are unable to self-care. Kidney transplant would be considered along this continuum assuming the patient was eligible (see Kidney transplant information on the next page).

Some patients are too unwell to care for themselves at home or have a strong reason (medical or personal) for not choosing home dialysis. This patient would commence dialysis in-centre hemodialysis.

Watch this video <https://www.youtube.com/watch?t=21&v=mi34xCfmLhw> a great overview of treatment options (10mins)

## Peritoneal Dialysis

St Vincent's has a large proportion of patients undergoing home peritoneal dialysis with overnight peritoneal dialysis or automated peritoneal dialysis (APD) the most popular options. Here are some resources to help understand peritoneal dialysis (PD):

[http://www.kidney.org.au/cms\\_uploads/docs/kha\\_a4\\_fs\\_1408\\_peritoneal-dialysis.pdf](http://www.kidney.org.au/cms_uploads/docs/kha_a4_fs_1408_peritoneal-dialysis.pdf)

<https://vimeo.com/70528942> peritoneal introduction (4min)

<https://vimeo.com/70530163> my life and PD (7min)

<https://vimeo.com/70532072> manual peritoneal dialysis or CAPD (2.30min)

<https://vimeo.com/70532963> automated peritoneal dialysis (2.30min)

Patients are taught how to perform peritoneal dialysis over a week and are then monitored over the phone and with quarterly home visits. We have a team of specialist nurses who perform the PD training and patient follow-up. The patient needs to continue seeing their nephrologist and visit the unit every 6 months for a test of the dialysis efficiency.

## Home Hemodialysis

Home hemodialysis (HHD) is more complicated and takes longer to learn than peritoneal dialysis. We have a smaller percentage of patients doing home haemodialysis at St Vincent's which is reflected nationwide.

Here are some resources to help understand home haemodialysis (HHD):

[http://www.kidney.org.au/cms\\_uploads/docs/home-haemodialysis-fact-sheet-dec-2014.pdf](http://www.kidney.org.au/cms_uploads/docs/home-haemodialysis-fact-sheet-dec-2014.pdf)

<http://homedialysis.org.au/>

<https://vimeo.com/44807834> HHD over view (2.30mins)

<https://vimeo.com/44810697> (7mins) patient's perspective

HHD takes between 6-12 weeks to learn. The training is done while the patient is having dialysis. We have a specialised team of nurses who perform the HHD training and follow-up the patient, similar to the model used with peritoneal dialysis.

## In-centre or Hospital Based Hemodialysis

Patients who choose not to do dialysis at home have in-centre, satellite or hospital based dialysis. This involves the patient attending the dialysis unit three times a week for 5hrs of treatment. There are dialysis units across Melbourne and Victoria that are run by the main public hospitals. St Vincent's manages the following dialysis services; St Georges Kew, Werribee, Sale, Shepparton, Swan Hill and Warrnambool. There is a mix of patients that attend these units, generally though they are frail and unable to do their dialysis at home.

[http://www.kidney.org.au/cms\\_uploads/docs/kha\\_a4\\_fs\\_1408\\_haemodialysis.pdf](http://www.kidney.org.au/cms_uploads/docs/kha_a4_fs_1408_haemodialysis.pdf)

[http://www.kidney.org.au/cms\\_uploads/docs/access-for-dialysis-fact-sheet-may-2014.pdf](http://www.kidney.org.au/cms_uploads/docs/access-for-dialysis-fact-sheet-may-2014.pdf)

## Kidney Transplant

One in ten of St Vincent's patients are eligible for a transplant. Patients are assessed for a transplant before and/or after they commence dialysis. If they are deemed fit for surgery they are listed on the deceased donor waiting list. Patients can receive a donated kidney from a relative, loved one, friend or altruistic donor. This can be done prior to needing dialysis or whilst on dialysis. Kidney transplants are considered the gold standard in treating renal failure. Currently, 50% of transplanted kidneys will function for 12years. The average waiting time for a deceased donor transplant is 4 ½ years. It is not uncommon for a person with ESKD to receive 2 or more donated kidneys during their lifetime.

[http://www.kidney.org.au/cms\\_uploads/docs/kidney-transplant-fact-sheet-jul-2014.pdf](http://www.kidney.org.au/cms_uploads/docs/kidney-transplant-fact-sheet-jul-2014.pdf)

## Supportive Care

The patients we care for rarely present with kidney disease alone. Often they have several chronic conditions; most commonly type 2 diabetes and heart problems. Due to the burden of these chronic conditions some patients receive little benefit from dialysis and choose to have supportive care. Supportive care involves active treatment of kidney disease but has a stronger focus on symptom management and end of life care. St Vincent's has a dedicated palliative care physician that attends the outpatient renal clinic and sees patients who have chosen to have supportive care.

[http://www.kidney.org.au/cms\\_uploads/docs/non-dialysis-supportive-care-a-treatment-option-fact-sheet-june-2014.pdf](http://www.kidney.org.au/cms_uploads/docs/non-dialysis-supportive-care-a-treatment-option-fact-sheet-june-2014.pdf)

## Other Resources

[http://www.kidney.org.au/cms\\_uploads/docs/kha\\_a4\\_fs\\_1408\\_all-about-chronic-kidney-disease.pdf](http://www.kidney.org.au/cms_uploads/docs/kha_a4_fs_1408_all-about-chronic-kidney-disease.pdf) chronic kidney disease

[http://www.kidney.org.au/cms\\_uploads/docs/depression-and-chronic-kidney-disease-fact-sheet-dec-2014.pdf](http://www.kidney.org.au/cms_uploads/docs/depression-and-chronic-kidney-disease-fact-sheet-dec-2014.pdf) depression and chronic kidney disease

[http://www.kidney.org.au/cms\\_uploads/docs/kha\\_a4\\_fs\\_1408\\_nutrition-and-kidney-disease.pdf](http://www.kidney.org.au/cms_uploads/docs/kha_a4_fs_1408_nutrition-and-kidney-disease.pdf)

Nutrition and chronic kidney disease

<https://www.youtube.com/watch?t=21&v=mi34xCfmLhw> a good overview of treatment options



## A guide to using dialysis-specific material in KOHP

This resource offers subject areas to explore within each session based on common health issues for people having dialysis. This is designed to complement the broader descriptions of dialysis treatments and services also provided in this information pack. Please contact the research team if you would like further information about these topics.

### Session 1: OHP

Ideas that may be useful for people undertaking dialysis treatment include sleep log tracking, food tracking, exercise, walking, and flexibility, all which relate to overall health and dialysis.

More specific aspects of treatment that patients may be facing:

- 3 x week Haemodialysis (HD)
- Fluid restriction
  - o For haemodialysis – 0.5Lt – 1.5Lt per day depending on level of kidney function
  - o For peritoneal dialysis (PD) 1.0 – 2Lt per day
- Time
  - o PD overnight (every night) with machine for 8.5hrs
  - o Haemodialysis 3 x week 5hrs

When facilitating the 'What is health' OHP topic incorporate questions such as:

*“how did you/your family adjust to your diagnosis of kidney disease?” “do you/your family have particular beliefs about what it means to cope with dialysis treatment?” “do you have a sense of why some people develop chronic conditions like CKD?”*

Explore how satisfied participants are with day-to-day functioning (prompts suggested below):

- What do I enjoy?
- What can't I do?
- Has my health improved? Consider different areas of health: Appetite, breathing, exercise tolerance, sleep quality

## Session 2: I Can Do Model Part 1, Health Plan 1

Vulnerabilities: consider exploring the patient's perceptions of the causes of the kidney disease

Explore links between the dialysis routine and the I Can Do Model

- Time required to attend and manage health needs
- needles
- fluid control
- waiting for transplant
  - o 4.5yrs on average
  - Potential Complications participants may experience
    - o Fistula problems (needling)
    - o Dialysis machine problems
    - o Tube/catheter problems if on PD, i.e. not draining fluid

Strengths: consider exploring participant experiences with family, partner, what helps their sense of wellbeing

- A useful open-ended question such as *“Do you ever think about what the future holds for your treatment?”* may facilitate discussion about complications or concerns about condition progression and impact on quality of life. A useful related question to promote hope *“How would you like your life to be in the future?”*

## Session 3: I Can Do Model Part 2, Health Plan 2

Consider exploring how participants feel towards these areas of health:

Fatigue

Appetite (eating patterns)

Water intake vs. fluid restriction (.5 -1.5Lt per day)

To explore participant perceptions of cognitive/intellectual health (see OHP health wheel), ask how healthy they feel in their attention, thinking and concentration. If they wish to explore this in more depth, you might ask whether this area of health has changed or been stable through their lives. You can help link these ideas back to the overall I Can Do model.

## Session 4: Medication

Metabolic monitoring/tracking is optional and more directing patient to follow-up results with a specialist/nephrologist. Ask participants which items on the monitoring list are most relevant to them.

Here is a list of common side effects of renal failure and the medications used to treat. Your role as a Program Assistant is not to advise about treatments, but having this knowledge may assist you to understand the patient's care experiences.

Anaemia can lead to feelings of tiredness, shortness of breath, dizziness, depression, confusion, feeling cold, trouble sleeping, and lack of appetite. This is because there are not enough red blood cells in your blood to carry oxygen around the body.

For people with kidney disease, the most common treatment is injections of an **artificial erythropoietin (EPO)** known as **Aranesp or Eprex**. Many people are taught to give themselves this injection and find it easy and convenient.

Bone Disease Bone pain, weak bones that break easily, itchy skin and joint pain are all signs of an imbalance in calcium and phosphate in kidney disease. Healthy bones need a balance of calcium and phosphate. This is partly controlled by vitamin D, a hormone usually made active by the kidney. Vitamin D helps to absorb calcium from food. When calcium and phosphate levels are not balanced the body also makes too much parathyroid hormone which further damages the bones.

Depending on the cause of bone disease and level of kidney function a doctor may prescribe medication such as **phosphate binders** like **caltrate, and active vitamin D calcitriol, and cinacalcet**. The length of time on dialysis can be adjusted to help bring the calcium and phosphate levels into balance. Some people may need surgery to remove their parathyroid glands to help control high phosphate levels and high parathyroid hormone levels.

Blood Pressure Blood pressure is the pressure of the blood in the arteries as it is pumped around the body by the heart. If you have chronic kidney disease, it is recommended that your blood pressure is maintained consistently below 140/90 mmHg. Blood pressure is closely related to kidney function. High blood pressure can cause kidney damage and kidney damage can cause high blood pressure. High blood pressure damages the blood vessels to the kidney, making them thickened and narrowed. Uncontrolled blood pressure may lead to kidney failure.

Many people with high blood pressure on dialysis will need to take medication. Sometimes three or four different blood pressure medications are needed. It is important that patients take any blood pressure medication exactly as it is prescribed and they do not stop taking it or changing the dose without talking with the doctor or pharmacist first.

## Metabolic monitoring in OHP

If the participant is keen to follow-up up these results please refer them to follow-up results with specialist/nephrologist.

## Session 5: Collaborative Partners & Strategies

This session may focus on future planning to help with illness, family or friends knowing what to do if specific problems arise, e.g. fistula problems, or home dialysis patients (peritonitis) or receiving a call up for transplant.

These people listed below are part of the specialist care team the participant may wish to engage with if they aren't already.

Home dialysis nurse

Dialysis nurse

Transplant nurse

Nephrologist (kidney doctor)

[Kidney Health Australia](http://www.kidney.org.au/) <http://www.kidney.org.au/>

Renal social worker

- To identify any potential gaps it can be useful to look at the completed Collaborative Partners OHP exercise and ask if there is anything else they need in terms of support with dialysis. This discussion may help with identifying any external referrals that could be made
- Explore whether there are any barriers to engaging in supports e.g., financial, accessibility

## Session 6: Change Enhancement

This session offers opportunity to review the fluctuations in health over a specific period of time in the Timeline activity. This lends itself well to other session topics of envisaging the future and what changes the participant would like to make.

Participant perceptions of stressors and strengthening events may arise through discussion of the timeline, whether you focus on the past week, month, or year.

Consider if the participant would like to problem solve a concern related to their treatment e.g. around how they are coping with fistula, dialysis sessions, blood tests, appointments, transplant, transplant reviews, surgeries. The participant might also find it valuable to use the Timeline to track ups and downs in his/her health across dialysis treatment.



## Session 7: Visioning & Goal Setting

This session is great for helping participants shape vague goals (e.g. 'I want to lose weight') into more concrete steps. There is opportunity to explore a goal related to dialysis treatment, however, be guided by what else might be a priority for the patient. They do not have to choose a dialysis specific goal but can focus on other areas of life e.g. family, social, bearing in mind the holistic and integrated view of health OHP promotes.

## Session 8: Building Health Plans

This session provides opportunity to review the OHP Health Plans including plans relating to dialysis care.

The generic OHP content will cover you for this session. However, as it is a session for reviewing it may be useful to ask participants to recall whether anything has changed for them since the first OHP session with respect to dialysis e.g., *“do you feel your beliefs about dialysis have changed in any way or stayed the same since session 1?”*

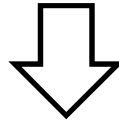
Introduce the concept of rewarding or acknowledging progress made towards goals. If you wish you can explore a dialysis-specific goal that has been identified. Explore whether participants have ever considered the idea of using rewards to improve progress, what they feel about this idea, and how they have rewarded themselves in the past. Emphasis is that rewards don't need to be big, expensive items but can be smaller, non-material things e.g., taking a long bath after a day of hospital appointments.

## Booster

The generic OHP content will cover you for this session. However, as it is a session for reviewing it may be useful to ask participants to recall how they have been managing without regular OHP contact. This is also an opportunity to review whether there are any external referrals that may be required as participants finish with their facilitators. It is important that throughout the program the eventual ending is discussed e.g., *“we are at Session 6, with 3 sessions to go, how are you feeling about the program coming to an end?”*

As such this session is an opportunity to say goodbye, allow participants to talk about their experience in the program (especially with dialysis support) and for you as facilitator to provide the participant with some positive feedback about their participation.

# Kidney Optimal Health Program



Session 1



Session 2



Session 3



Session 4



Session 5



Session 6



Session 7



Session 8

Optimal Health – What is Health?

Living with chronic kidney disease: mind, surrounds, body

I Can Do Model Part 1 – Strengths and Vulnerabilities (Understanding the balance)

Exploring the treatment regimen and beliefs about CKD and dialysis

I Can Do Model Part 2 – Strategies and Stressors (Understanding and monitoring impact)

Reflecting on cognitive/intellectual health during CKD and dialysis

Medication – Medication and Physical Health

Common medications and side effects for people with CKD

Collaborative Partners & Strategies – Identification of key partnerships (Connecting with key people)

Support networks

Change Enhancement – Understanding past events and defining change

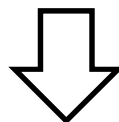
Observing fluctuations across time in dialysis and CKD

Visioning and Goal Setting – Creative problem solving and planning (Developing, setting and celebrating goals)

How problem solving can support dialysis treatment

Building Health Plans – Health Plan I, II & III (Maintaining Well-being)

Building rewards into the health plan



Booster