

Kidney Supportive Care - a guide for patients and families

Living well without dialysis

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If you decide not to have dialysis, we will manage your kidney disease with kidney supportive care.

Kidney supportive care (sometimes called conservative care or maximal supportive care) is an active form of treatment provided by your kidney team. It focuses on maintaining a good quality of life that is right for you and for as long as possible but it never replaces your kidney function as dialysis does.

How you can protect the kidney function you have



Making sure your blood pressure is well controlled.

Good blood pressure control is key to keeping you as healthy as possible. Having well controlled blood pressure will protect the kidney function that you have and help make your kidneys work for as long as possible. Good blood pressure control also helps protect you against heart attacks and strokes.



Together we can reduce the chances of this happening by:



Checking your blood pressure regularly.



Prescribing you blood pressure tablets. Taking these regularly is one of the most important ways you can protect your health.



If you are still passing urine, prescribing water tablets (often called diuretics) that will help in removing excess fluid from your body.



Involving a dietitian who will be able to advise you on changes you can make to your diet to help control your blood pressure better, such as reducing your salt or managing your weight by reducing your calories.



Giving you advice on taking gentle exercise where possible - even if it standing up every hour from your chair.



Giving you advice about how to restrict the amount of fluid you drink if you struggle to pass urine, as too much fluid can raise your blood pressure.



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Making sure that blood sugar levels are well controlled if you have diabetes.



Test your sugars.



Take your medication for diabetes.



Follow dietary advice.

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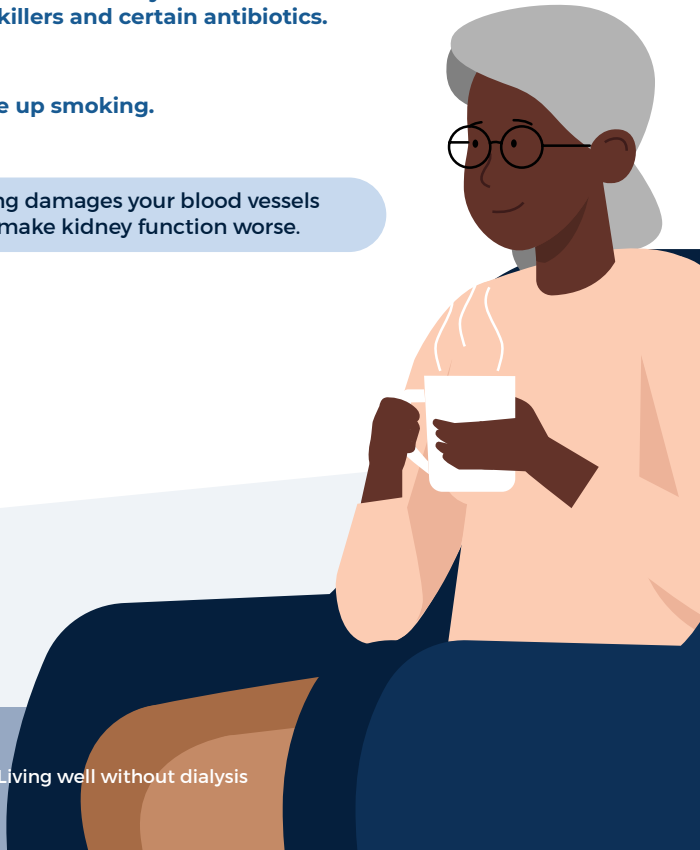
Make sure your tables are kidney safe. Avoid medications such as such pain killers and certain antibiotics.

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Ask for help to give up smoking.



Smoking damages your blood vessels so can make kidney function worse.



Symptoms and quality of life

As your kidney function declines over time you may experience a worsening of your symptoms or even some new ones caused by other conditions that you have.

The list of symptoms may look quite daunting but not everyone gets all the symptoms and some people may get very few symptoms. If you do experience symptoms, there are lots of good treatments which can help improve them.

Regardless of whether the symptoms arise from the kidney disease, we aim in partnership with you, your family and other medical teams to treat and manage any symptoms with the goal being to maintaining your comfort and quality of life.

It is really important to us to know what symptoms you have each time we see you and in order to do this we may go through a checklist. This will help us agree with you on what support to offer to keep you living well.



You may experience some swelling in your ankles, feet and hands if you have kidney disease and become more short of breath. These can all be signs of too much fluid in your body.



You may be advised to reduce your daily fluid intake, including fluids in food like soups and yoghurts, to help relieve the swelling.



You may also be advised to reduce the amount of salt in your diet because high levels of salt encourage water retention.



You may also be given water tablets (otherwise known as diuretics).

Symptoms & causes



Loss of appetite, nausea and sickness.
Increased levels of toxins in blood.



Tiredness or fatigue.
Anaemia.
Sleep disturbance due to low mood, itching, restless legs or cramps.
Body's response to becoming less well and things slowing down.



Itch.
Increased levels of toxins in blood.



Pain & Mobility.
Many causes, often not directly caused by kidney failure.



Restless legs or cramps.
Build up of toxins and changes in the electrolyte levels in the blood such as magnesium.



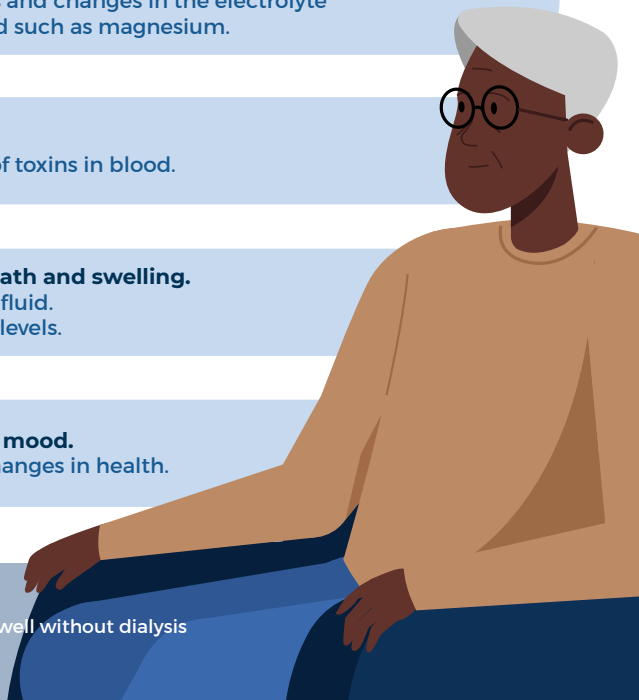
Constipation.
Increased levels of toxins in blood.



Shortness of breath and swelling.
Too much excess fluid.
Low bicarbonate levels.



Anxiety and low mood.
Adjustment to changes in health.



What we can do to help



Loss of appetite, nausea and sickness.

Anti sickness tablets.
Dietitian to support nutrition.



Tiredness or fatigue.

Managing specific cause.
Psychological support sometimes helpful.
Correct anaemia with EPO Help with fatigue management.



Itch.

Medications (antihistamines) and moisturising creams.



Pain & Mobility.

Treat the underlying cause taking kidney disease into consideration.
Refer you to see a physiotherapist or an occupational therapist.



Restless legs or cramps.

Exercises, electrolyte replacement, and other medications.
Tonic water (containing quinine) may also help cramps.



Constipation.

Dietary advice, careful review of other medications and laxatives.



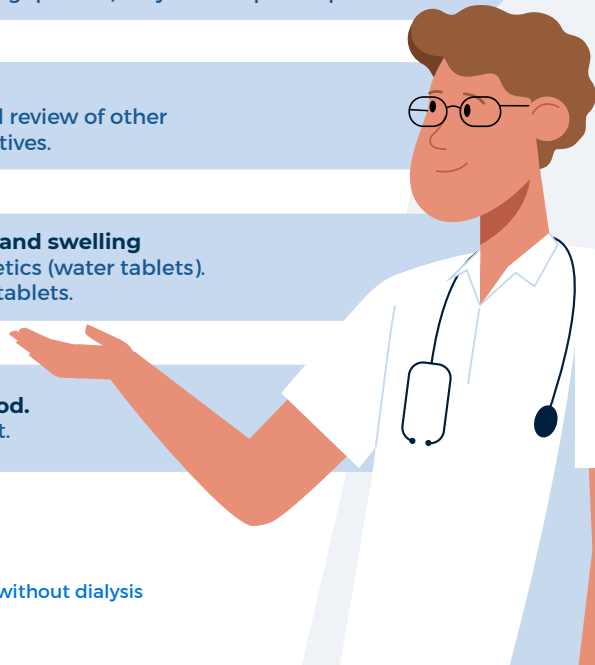
Shortness of breath and swelling

Fluid restriction, diuretics (water tablets).
Sodium bicarbonate tablets.



Anxiety and low mood.

Psychological support.



Other things to keep you as well as possible

- 1** Ensuring that your general health is as good as it can be ensuring you take preventative measures such as having your annual flu jab.
- 2** Giving you advice on a healthy diet and lifestyle.
- 3** Ensuring you have access to psychological, spiritual and social support if you need this.
- 4** Regularly assessing and treating symptoms that can be associated with kidney disease.
- 5** Although kidney disease can be associated with a lot of symptoms there are things we can do to help which don't include dialysis treatment.
- 6** Changing tablets or diet can often be really helpful.
- 7** If you are struggling with your mood or fatigue, exercise of psychological care can really help.
- 8** Ensuring you have access to services to support you with your daily life e.g. physiotherapy or occupational therapy.
- 9** Ensure you have the support you need close to home e.g. community services such as local symptom control teams.





This booklet was created by the London Kidney Network Supportive Care Workstream. It is intended to be used to support conversations with your kidney doctors and nurses. The information in this leaflet doesn't replace or superceed their advice which is specific to you.

If you have any questions, please talk to your doctor.

londonkidneynetwork.nhs.uk