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Roche would like to thank the following contributors who have kindly offered their expertise in developing this programme:

**Authors**

**Clinical Content**
Natasha McIntyre  
RGN, MSc

Diane Green RD, BSc (Hons)  
Renal Dietitian, Salford Royal Hospitals NHS Trust

Dr Christopher McIntyre  
Consultant Nephrologist, Derby Hospitals NHS Foundation Trust  
Associate Professor and Reader of Vascular Medicine University of Nottingham

Roche would like to thank the Advisory Board Members:

**Advisory Board Members**
Timothy F Statham OBE, Chief Executive, National Kidney Federation  
Marion Higgins, Patient Representative  
Michael Scott, Patient Representative  
Chris Payne, Patient Representative

Carol Anderson, Advanced Kidney Care Manager; Belinda Dring, Anaemia and Predialysis Nurse Specialist; Lynn Fullerton, Anaemia Nurse Specialist; Helen Hurst, Advanced Nurse Practitioner; Catherine Johnson, Anaemia and Predialysis Sister; Jane Macdonald, Lead Nurse, Renal Services; Kate Taylor, Practice Development Lead; Jackie Waller, Anaemia Co-ordinator; Gillian Wood, Anaemia Co-ordinator
Message from the NKF
Message from the NKF

When patients are diagnosed with chronic kidney disease (CKD), they are generally well informed by their healthcare professional about what to expect in terms of treatment for their condition or the need for regular dialysis visits.

It is important to remember, however, that many aspects of managing kidney disease can be instigated by the patients themselves. For example, for many patients, it is vital that fluid intake is regulated throughout the day. How this can be achieved is something that patients should be encouraged to do for themselves.

However, in order for the patient to manage their own condition as best as possible, renal units need to be able to educate individual patients and encourage them to take control of their condition. The National Kidney Federation fully supports the launch of the time programme as a valuable resource that renal units can use to achieve this goal, working hand in hand to empower their patients to become involved in their renal care.

Patient education, motivation and empowerment will ultimately prove to be the best way to improve patients’ long-term outcomes and overall wellbeing.

Timothy Statham
Chief Executive
National Kidney Federation (NKF)
Foreword
Foreword

"...the hardest part of my diet is not drinking..."
"...salt... don’t touch it"

These are comments I hear everyday from patients. Fluid is much more than food and drink; it plays a vital part in your daily life. Often the first thing you get offered when you visit friends is a cup of tea or coffee. What it worse is that many people who have to restrict their fluid intake are not aware of the link between a diet that is high in salt, thirst and keeping within their fluid allowance. The majority of salt comes from pre-packaged foods. Most people are eating too much salt without even realising it. Good practical information will help to control your thirst, the amount of fluid that you drink and to protect your heart.

Diane Green
Renal Dietitian, Salford Royal Hospitals NHS Trust
Introduction
Introduction
Managing your fluid intake is very important for kidney dialysis patients. Normally your kidneys are responsible for removing extra fluid from your body. But when your kidneys fail they can no longer do this. Dialysis can only remove some of the extra fluid from your body, so you need to make sure you consume less fluid.

Disclaimer
This information is provided for guidance purposes only. Please note that each patient is treated on a case-by-case basis. Some information may not be relevant to your needs, and so it is important that you consult your doctor or dietitian before following any of the advice outlined below.
How to use
Salt and fluid management programme user guide

About time
The time programme is an information resource for people with kidney disease. It aims to promote greater understanding about kidney disease and about the treatments that people with kidney disease receive. The time programme also hopes to provide tips and guidance about what you can do to improve your experience as a kidney disease patient. The word time has been chosen as the title for this programme because with a little time and focus, great gains can be made.

This programme has been developed by healthcare professionals and patient representatives. The materials that are available to you as part of this programme are described in more detail below.

Please ask the staff in your kidney unit if you have any questions about the programme and/or any of the information in it, as they have been trained to know about the time programme and are available to offer assistance in any way they can.

time salt and fluid management programme
The time salt and fluid management programme explains the impact of having too much salt or fluid, and gives guidance on how to manage the intake of fluid in your daily life.

The following guide briefly explains the materials that are available in the salt and fluid management programme and how they may be used. If you are interested in seeing any of the materials outlined here, please speak to the staff in your renal unit.

Posters
The posters are designed to let people know about the time programme and start them thinking about salt and fluid management.

Flashcards
The key messages in the salt and fluid management programme are presented on flashcards. You might see the flashcard books present in the renal ward. They are designed to give clear and consistent messages in a short space of time. In addition to the key message, each flashcard shows a frequently asked question, the answer to which is revealed on the back of the card.
Patient information manual
This guide contains more detailed information than the flashcards. It will be kept on the ward so that you can read it during your treatment visits.

Healthcare professional information manual
There is also a guide for kidney unit staff so that they know what is contained in the time programme and how to assist you with any of the suggested activities.

Top tips cards
The top tips cards are available in two sizes. They outline tips on managing your intake of salt and fluid and have space for you to keep track of your blood pressure and weight.

Reusable ice cubes
Reusable ice cubes are a handy way to keep drinks cold without adding to fluid intake.

False bottomed mug
The false bottomed mug is designed so that you can have a smaller drink while using a normal sized mug.

500ml jug
The 500ml measuring jug is available to help you measure how much you are drinking.
Key messages
Key messages

The key messages that you should understand when discussing the importance of fluid management with your nurse are:

- Sodium is an important mineral that controls blood pressure
- Salty fluids or foods will increase thirst and make you drink more
- If you are on dialysis, you need to be very careful about your liquid intake so that you do not become fluid ‘overloaded’
- If you are on haemodialysis, it is recommended that you gain no more than 1.5-2kgs in between dialysis sessions. Or if you are on peritoneal dialysis, you should also try and stick to your fluid restriction
- Fluid ‘overload’ can result in breathlessness, swelling, high blood pressure and eventually over time, enlargement of the heart and heart failure
- Excessive weight gain between dialysis sessions means that you need to cut back on your salt and water intake
- If you have diabetes, good control of blood sugar levels will help to control your thirst
- Fluid can come from obvious sources (drinks) but also from foods with high water content such as ice cream, custard, ice cubes and gravy
- The less urine your body makes, the less fluid you can drink
- Most dialysis patients have a fluid restriction of 500-700mls, plus the previous day’s amount of urine output. (i.e. if you urinate 300mls in a 24-hour period, your fluid intake can be 1000-1200mls in 24 hours)
- Too much fluid intake may result in a longer dialysis session or more frequent dialysis
- One teaspoon of salt contains approximately 2400mg of sodium
- If you are on haemodialysis, your sodium intake should be restricted to 1600-2000mg per day (depending on your urine output)
- Controlling sodium intake will help to avoid cramping and blood pressure drops during dialysis
- Too much sodium will make your body retain fluid which can be detrimental to your health
- Salt substitutes such as ‘Lo-Salt®’, ‘Selora®’, ‘Ruthmol®’ should never be used if your kidneys are not working properly
- Seek advice from a renal dietitian if you are having difficulties with your diet
Fluid intake and dialysis
Why is too much fluid bad for you?

You are receiving dialysis because your kidneys are not working properly and this causes fluid to build up in your body. If you come to your dialysis appointment with too much fluid, it can make you feel unwell afterwards. Your blood pressure will drop quickly, and you may feel dizzy or faint. You may also have headaches, feel sick, and you may have muscle cramps (painful contraction of muscles). This is because extra fluid has to be removed during the dialysis session.

Taking in too much fluid can cause lasting damage. Excess fluid causes high blood pressure, and makes your heart work harder. It can become enlarged and damaged which leads to heart failure. Excess fluid can build up and cause swelling (oedema) in your feet and legs. You may also find it harder to breathe if fluid builds up in your lungs.

By controlling your fluid intake, you can help to stop these problems from happening. This will make you more comfortable throughout your course of dialysis treatment.

How much fluid are you allowed to consume each day?

You are normally allowed to drink up to 500-700ml of fluid every day, plus the amount of liquid that you would normally urinate in a day. For example, if you urinate 500ml every day, your maximum fluid intake would be 1000-1200ml. The amount of urine you produce in a day will be measured to find out your maximum daily fluid intake.

Patients on peritoneal dialysis (PD) are not as restricted with their fluids as people on haemodialysis. This is because PD can be performed everyday, meaning that fluid does not build up over a long period of time. However your dialysis solution is high in glucose, which raises blood glucose levels and stimulates thirst. Therefore you should still keep track of your fluid intake and the fluid which is removed after dialysis exchanges.

Diabetic patients undergoing dialysis need to watch their sugar intake as well as their fluid intake. High blood glucose stimulates thirst, so it is important that you maintain good blood glucose levels to manage your thirst and prevent fluid overload.

What is my dry (target) weight?

Your dry weight is your body weight when you do not carry any excess fluid. This should be your target weight after a dialysis treatment. By maintaining your dry (target) weight, you will feel better after dialysis. You will also help to protect your heart from long-term damage.
How will exercise affect my fluid intake?

If you exercise, some fluid may be lost as sweat. This means that exercise may change your fluid requirements and it is advised to seek professional advice before you start an exercise programme. Your dietitian or another member of your healthcare team will advise you on your specific needs. Remember it is dangerous to exercise when you are carrying excess fluid because of the extra strain on your heart.

What counts as a fluid?

Any food that is liquid at room temperature will count towards your fluid intake. Some examples of fluids include water, tea, coffee, fizzy drinks, fruit juices, milk, alcohol, soup, ice cream and ice lollies. Some foods with high water content are considered equivalent to fluids too, such as watermelons, grapes, oranges and cucumbers.

Some of the foods that contribute to your fluid allowance.

<table>
<thead>
<tr>
<th>Soft drinks</th>
<th>Coffee, tea</th>
<th>Water, milk, juice</th>
<th>Ice cubes, ice lollies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Milkshakes</td>
<td>Frozen desserts</td>
<td>Soup</td>
<td>Alcoholic beverages</td>
</tr>
</tbody>
</table>

How can I measure the amount of fluid intake?

The table below gives an indication of the amount of fluid that is typically contained within each of the items. You can use these measurements to estimate your individual consumption and to ensure you don’t exceed your maximum allowance.

<table>
<thead>
<tr>
<th>Container</th>
<th>Fluid capacity (ml)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A mug</td>
<td>300</td>
</tr>
<tr>
<td>A glass</td>
<td>200</td>
</tr>
<tr>
<td>A small cup</td>
<td>150</td>
</tr>
<tr>
<td>A tablespoon</td>
<td>15</td>
</tr>
<tr>
<td>A small ice cube</td>
<td>15</td>
</tr>
</tbody>
</table>
Salt
What is sodium chloride and why is it important?
Sodium chloride is table salt, and its most common use is as a seasoning in foods. It is used in processed foods to add flavour and is also a preservative. In the body, sodium is an electrolyte which means it controls the amount of fluids entering and leaving the body’s tissues. It also helps to regulate blood pressure and is vital in transmitting nerve impulses.

How is salt linked to fluid intake?
Normally, the kidneys are responsible for removing excess salt (sodium chloride). Excess salt in the body makes you thirstier, making you drink more, and can therefore increase your fluid intake which can cause your body to build up water. As with drinking too many fluids, high salt intake will increase your blood pressure and can lead to heart failure. This can result in swelling of the hands, legs and face as well as difficulty in breathing. Following a low-salt diet will help to prevent fluid build up, and make dialysis treatments more comfortable.

How much salt is allowed per day?
Patients with kidney disease should follow a low-sodium diet, typically including 1600-2000mg of sodium per day. Your dietitian will recommend a suitable daily intake of sodium.

How can you manage your sodium (salt) intake?
It is advisable to speak with your dietitian in order to determine the salt content of the foods your normally eat, and find out ways in which your salt intake can be reduced. Your dietitian will also try to help you to change your habits, such as not using salt when cooking and by using natural ingredients such as herbs and spices to add flavour. Eventually you will begin to appreciate foods without added salt.
Keeping a food diary
You may be asked to keep note of your meals in a food diary. This can be used to make changes to your diet if you continue to experience symptoms of fluid-overload. By using a diary you can monitor your salt intake and see whether you are reaching the target your dietitian has outlined.

Salt substitutes
Please consult your dietitian before using salt substitutes such as 'Lo-Salt®', 'Selora®' or 'Ruthmol®'. They contain other substances related to sodium, such as potassium, that should be avoided by patients with kidney disease.

Find new ways to generate flavour
By using fresh herbs and spices, you will find less need to add salt to your food. Wine can be used to add flavour to sauces, and if this is reduced whilst cooking this will also reduce the alcohol content and fluid volume of the sauce, whilst enhancing the flavour.
Determine the salt content of foods by reading their labels

Food labels should indicate the amount of sodium or salt contained within the food item, as well as traditional ingredients and nutritional information. Ensure these amounts comply with your targets. Remember some drinks also contain added sodium or salt, so check their labels too.

Most people find food labels very confusing as salt can be listed as either salt (g) or sodium (g). The government uses the three simple steps below to help people:

Calculating the salt content of food

To convert sodium to salt:
1. Find out how much salt there is in 100g of the food:
   To do this, look at the food label and multiply the amount of sodium listed per 100g by 2.5.
   e.g. 1g of sodium per 100g = 2.5g of salt per 100g

2. Then calculate the amount of salt found in 1g of the food:
   e.g. 2.5g of salt in 100g of food = 0.025g of salt in 1g of food

3. Then calculate how much salt there is in the number of grams of food you are eating:
   e.g. (0.025g of salt in 1g) x 30 = 0.75g salt in a 30g serving

Avoid processed and preserved convenience foods

These are usually high in salt in order to preserve shelf-life. Try to find alternative, fresh sources of food, which can often be cheaper and healthier. Some canned foods can be stored in sunflower oil rather than brine (salty water) so look out for these alternatives too.

Eating out

Be aware that many convenience and fast foods are high in sodium. If you are eating out at restaurants, make sure you notify the person serving you that you would like your meal to be prepared with little or no salt.

High salt intake can lead to increased fluid intake and may cause the following symptoms:
- Raised blood pressure
- Swelling, especially around the ankles and lower legs
- Breathlessness

By modifying your diet to take in less salt (and therefore less fluids) you may be able to control or reduce some of these symptoms.
Controlling thirst
How can I control my thirst?

- Salt activates the thirst mechanism in the body. By eliminating salt from your diet you can actually reduce your desire for fluids. Hot and spicy foods also stimulate thirst.
- Sometimes thirst can be a side effect of medication. Consult your doctor to ensure the medications you are taking are not causing excessive thirst; they may be able to recommend alternatives.
- Chewing gum or sucking sweets can help to prevent thirst by stimulating saliva production. Allowing an ice-cube (15ml of water) to sit in your mouth may also help. Sour sweets (sherbets) or lemon/lime wedges will satisfy thirst too. If you are diabetic, try to find sugar free sweets.
- Distribute your fluid allowance throughout your day, and take sips when drinking in order to make the sensation last longer.
- Take medication with your meal unless directed otherwise by your doctor.
- Keep cool by staying out of the sun, and drink cold rather than hot drinks. You could freeze some fruits and snack on these between meals.
- Rinse your mouth out with water or mouthwash to combat the feeling of a dry mouth, or alternatively you can brush your teeth.

What about diabetic patients and glucose levels?

If you have diabetes, your body finds it difficult to control your blood glucose levels. If your blood sugar levels are poorly controlled, you will become more thirsty and want to drink more. Managing your diabetes by following your dietitian’s and other health care professionals advice will help you to control this.

What about patients on peritoneal dialysis (PD) and glucose levels?

If you undergo peritoneal dialysis, you will be aware that the dialysis solution used to collect waste products and extra fluid from your abdomen is high in glucose. This means that your blood glucose levels will be higher after a dialysis session which may cause thirst. You need to manage your thirst because fluid overload can still a problem with PD patients.

Salty foods that you should try to avoid:

- Cured meats such as bacon, ham, tinned meat
- Smoked fish, canned fish in brine
- Salted biscuits
- Salted crisps, nuts, Bombay mix and goats cheese
- Meat and yeast extracts (e.g. Bovril®, Marmite®, Oxo®), tinned and packaged soups
- Cheese – except cottage and cream cheese
- Bottled sauces (e.g. ketchup, Worcestershire sauce, soy sauce)
- Manufactured flavourings (e.g. garlic or celery salt, sea salt, curry pastes)
What about alcohol?

For healthy adults, the consumption of alcohol within normal guideline amounts (2 units a day for women and 3 units a day for men) usually has no long-term effect. However, patients undergoing dialysis and taking medication need to be treated differently.

- If you are on medication, you should avoid drinking alcohol because it may interfere with how your medication works.
- High blood pressure associated with kidney disease is harder to control when alcohol is present in the body.
- Alcohol can damage the kidney cells.
- The extra calories in alcohol can increase your weight.
- Alcohol has been shown to be beneficial in low amounts when preventing heart disease. However, it should be noted that any benefit can be achieved by regular exercise and a healthy diet. Drinking alcohol solely for its protective benefits on the heart is not advised.
- The maximum daily amount of alcohol renal patients can consume is 2 units for men, and 1 unit for women.

Fluids containing high levels of sodium or glucose:

- Fruit and vegetable juices
- Beers, lager, cider, sweet wines and sherry
- Oxo®, Bovril®, Marmite®, and other meat and vegetable extracts
- Cocoa, drinking chocolate, malted milk drinks such as Ovaltine® and Horlicks®
- Evaporated and condensed milk

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Getting on with everyday life
### Out and about – getting on with everyday life

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
<th>What should I ask?</th>
</tr>
</thead>
</table>
| How can I manage my fluid intake in social situations without standing out? | • If you know you are going to attend an event, try to save up some of your fluid allowance if you know you intend to drink socially, to ensure you don't exceed your daily intake.  
  • Fill up a glass with ice, and a small amount of fluid. Try to drink only small sips of fluid so your drink lasts longer.  
  • Ask for your glass not to be refilled.                                                                                           | • Ask your healthcare team how other patients manage their fluid intake in everyday life.                                                  |
| How can I take my pills without using up too much of my fluid allowance? | • To swallow pills: Put the pill in your mouth with a sip of fluid. Tilt your head upwards to the ceiling. Let the pill sink to the back of your throat and then swallow.  
  • To swallow capsules: Put the capsule in your mouth with a sip of fluid. Look downwards to the floor. Allow the capsule to float to the back of your throat and swallow. | • Can I take my pills with a meal?  
  • Can I take different types of pills together to minimise fluid intake?  
  • Are there any medications that are easier to swallow?                                                                              |
| I am always thirsty. How can I manage my thirst without exceeding my fluid intake?                                              | • Rinse your mouth out with water.  
  • Avoid salty or spicy foods.  
  • You can chew gum, or suck on a boiled sweet, a slice of lemon or an ice cube.  
  • Try to remain cool.  
  • Ask your doctor if any medications you are using cause thirst as a side effect.                                                | • Can I increase my fluid intake if I sweat from exercise or hot weather?  
  • Is thirst a side effect of my medication? If so, are there alternative medications that don't cause this effect?                  |
Patient stories
Patient stories

Sarah
Sarah is a 46-year-old housewife and mother of three adult children. She has been on haemodialysis for the past year.

“When I was told I needed to go on dialysis because my kidneys were failing, I was really scared. I was told by my family and friends that I should drink lots of fluids, more so than a healthy person because it clears the blood.”

Soon I was finding it hard to breathe, and had swelling in my hands and legs. When I went to have my dialysis treatment, I felt really dizzy, tired and faint afterwards. My doctor told me I was consuming too many fluids, and that what I was doing was wrong. I should have been limiting my intake of fluids and looking at how much salt I was having in my diet.

Now that I have been controlling my salt and fluid intake, I have found dialysis treatments to be much more comfortable. When I drank too much, I used to have high blood pressure that dropped really quickly after dialysis. This used to make me feel faint and sick. Now that I have managed my fluids, my blood pressure remains relatively normal, and that’s good news for my heart too.”

Will
Will is 27, and is a website developer. He has been on haemodialysis for two years and is awaiting a kidney transplant.

“Being so young I couldn’t understand why my kidneys were failing. It was a real shock. I was an active person who loved going out on weekends. I kept myself in good shape by playing football and regularly going to the gym. The restrictions on what I could eat and drink were going to be really tough, especially because I am a very social person and love going out for a drink after work.

My dietitian advised me on my daily fluid allowance and the foods I should avoid eating, but I found it very difficult to change my dietary habits. After a while, I became used to eating food without salt and made recipes interesting by incorporating spices and herbs. I buy foods that contain very little or no salt. I love tuna sandwiches, so now I make sure I buy tinned tuna stored in sunflower oil, not in brine which is too salty. I’m really careful to look at packaging on food to make sure the sodium content is low.

When I go to restaurants I try to make sure I avoid highly salted food, and often ask the chef not to use salt when preparing my food. If the food contains sauces or dressings I ask for these to be served separately so that I can control how much I need to add to my food. They are always happy to accommodate my needs which makes me feel at ease. When I first went to the pub, I found it quite restrictive to stick to one small drink. But to make it last longer I often take small sips. If I feel thirsty I just take the lemon slice or ice cube from my glass and pop it into my mouth. It does the trick and keeps me within my fluid allowance.

I can really feel the benefit of managing my fluid intake. My dialysis treatments are more comfortable, and I feel more energetic when I want to play football.”
Margaret
Margaret is 80 years old and is a retired nurse. She has been on haemodialysis for two years and is also diabetic.

“I was not scared when I was told my kidneys were failing and that I would have to go onto dialysis three times a week. Being a nurse I knew about haemodialysis, how it worked and what it involved. I was always giving people information that I knew would make life better, so I made sure I followed all the advice I was given by my healthcare team because I knew they had my best interests at heart.

I didn’t have too many problems changing my diet because I always ate healthily anyway. I made sure I kept to my fluid allowance too, although it did mean I had to cut down on my cups of tea! But being diabetic meant that I had to maintain good blood glucose levels too. This was because high blood glucose levels would have increased my thirst, and if I had taken on more fluid I would have been uncomfortable after dialysis and put more strain on my heart. You don’t need to be a nurse to know that your heart is a vital part of your body, and that you’d do anything to protect it.”

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