

## Information for Patients

### This leaflet explains:

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# Living with your Nephrostomy Tube

Now your tube is in, the urine from the kidney drains down the tube into the drainage bag. Below are some common questions asked by our patients. If you have a question not answered, please do not hesitate to ask the doctor, nurse or district nurse.

It may take a little time to familiarise yourself with the bags.

## Care of the tube and bags

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You will be shown how to do this whilst you are on the ward/out-patients department. Please be sure you are confident with this before you go home. Please speak to your nurse if you are not sure about anything.

There are different drainage systems available but at the RUH we have been using a urostomy bag (sticky bag attached to your skin with tube placed inside) with connector and leg bag. We have been using this type of drainage so that the tube cannot get pulled out and is 'tension free' inside the bag. If you do not get on with this form of drainage system then please speak to your district nurse about trying an alternative such as NephSys from Manfred Sauer (elasticated waist belt with drainage bags).

The **leg bag needs changing every 5 to 7 days** and the connector needs changing every week. The night bag should be changed every night. If this is not possible at home (as you have the reusable night bags with taps) please wash out daily.

The urostomy bag needs changing twice a week routinely but your district nurse may decide to change more or less frequently. If it becomes soiled or lifts off then the bag will need to be renewed. If the bag is left on for too long it makes it very difficult to remove the tube (as gets stuck in the bag) and can cause irritation to the skin.

To check the drain valve (white plastic valve at bottom of bag) is closed, the teardrop should be facing the body-worn side of the pouch. Be careful with this as it can be knocked open by accident, causing embarrassment – apply the cap if needed.

A no sting barrier film can be used to protect against skin irritation caused by urine, adhesives and friction. If the skin becomes sore or damaged around or under the bag then please let your district nurse know.

Your district nurse will come and do the urostomy bag changes for you. They will check everything is O.K at home and may teach you and your carers how to do this. The district nurse/GP Surgery will arrange future supplies of all the bags and accessories. It is difficult to change the urostomy bags without help as they are placed at the back.

Place urostomy bag so that the connections are facing towards front of leg to make it easier for attaching leg bag, emptying and for comfort.

## Preventing infection

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You need to drink 2 litres a day – 3 litres if you already have an infection. Ensure you wash your hands thoroughly before changing any of the bags and after. Your healthcare worker can give you more information about keeping hands clean and the correct way to clean your hands.

Keep the drainage bag closed at all times except when emptying. Empty the drainage bag only when necessary and not before. Keep any dressings or bags clean and change if soiled.

Cranberry juice is known to assist in the prevention of infections. If you like cranberry juice then have a daily glass – do not drink more than two glasses a day (400 ml). Cranberry juice should not be taken if you are on warfarin as can thin the blood and care should be taken if you are a diabetic.

If you have 1 nephrostomy tube then it is still possible to get an infection in the other kidney. If you notice symptoms of frequently going to the toilet, burning or stinging when passing urine, have a fever or feel unwell then take a sample of urine to your GP. Increase your fluid intake and take paracetamol (if you can).

## Eating and drinking

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You can eat & drink normally. You need to ensure that you have a good fluid intake each day – at least 2 litres.

## Exercise and sleeping

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Gentle exercise is fine. More strenuous exercise may cause pain & should therefore be avoided.

Lying on the side of the tube may be uncomfortable so try the other side. If you have tubes in both kidneys find a position that suits you. Do try to not let the tube (s) stop you from sleeping. Try to place the urostomy bag in a good position to allow the connections to be in the curve of the waist to avoid discomfort and to make it easier for sleeping.

## Painkillers

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For mild pain you can take paracetamol and ibuprofen (as per their instructions) and if you are able – wait about half an hour for tablets to work.

## Sexual intercourse

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There are no restrictions on sexual intercourse. You may be worried about dislodging the tube but remember the tube may have a stitch to secure, has a locking mechanism and is in a 'tension free' bag.

## Working & Driving

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Going back to work depends on your job. Light housework or office work is fine. Heavy labouring & certain jobs may not be. Please discuss with your Doctor for your particular job.

If you are comfortable and can do an emergency stop without thinking then you should be safe to drive. You should inform your vehicle insurance company.

## Holidays & Out and About

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This depends on the reason you have a nephrostomy tube. It also depends on how long you are going away for and to where. You need to be confident to look after your tube and you may want to check out the medical facilities. Check with your Doctor before leaving the hospital and your insurance company before you go.

Please feel free to get out and about as you are able. Knowing where the toilets are situated when you are out may alleviate fears about the bag getting too full. You will in time also develop an idea of how fast the bag takes to fill up and this will help you plan your days out. Do not let the bag overfill as it will become heavy and uncomfortable.

For longer days out a 'memory cushion' or some form of padding would be unobtrusive and offer some comfort especially in the car, train or eating establishments which may provide firmer seating.

## Passing urine

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If you have 1 nephrostomy tube we would expect you to pass urine in the normal way as well, as the other kidney will still be draining urine into your bladder.

If you have two nephrostomy tubes we would expect the tubes to drain all the urine so passing urine would be unlikely.

## Holding Tube in Place

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Sometimes a stitch is used to secure the tube when first inserted. The tubes we use have a locking mechanism, you may notice what looks like a 'thread' at the end of the tube, this is part of the locking mechanism and has no control on the flow of urine or workings of the tube. The stitch would need to be removed at 7 to 10 days.

## What happens next?

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Your doctor will explain to you what further treatment is required. This may include an operation at a later date, ultrasound wave therapy if you have a stone (the wave therapy machine comes to the RUH once a month) or keeping the tube in long term. If you have any questions about the treatment you are to have then please do not hesitate to ask the doctor or nurses looking after you.

Your tube if remaining in should be changed every 4 to 6 months. This is done in the X-Ray Department where you had it put in.

## Discharge from Hospital

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The ward staff/out-patient staff will make sure you are confident with the tube before you go home. You may like for some other family members or carers to be shown as well. Please let your nurse know if you have any queries, are not sure about anything or wish the nurse to go through everything with someone other than yourself.

The discharge summary will be sent to your G.P.

Any further appointments such as out-patient clinic appointment, wave therapy appointment (known as lithotripsy) or operation date will be sent to you in the post.

On your discharge you should have:-

- A letter to give to the District Nurse which will let them know what has happened to you and what the future plans are.
- Supplies to start you off which include – leg bag, disposable night bags, urostomy bags, connectors and stand.
- Nephrostomy Tube Guidelines leaflets – Flushing Nephrostomy Tube and troubleshooting guide.
- Information on what is going to happen to you next.
- Your own medications returned and any new ones from our pharmacy (normally for 28 days unless medication is for course e.g. antibiotic)
- Please ask the doctor if you need a sick note for work as the nurses can only complete sick notes for the time you have been in hospital.

## Other sources of information

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### **NHS Direct**

For health advice or information you can call NHS Direct on 0845 45647 or visit the website: [www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

RUH urology department website [www.ruh.nhs.uk/urology](http://www.ruh.nhs.uk/urology)

NHS Choices - Your health, your choices [www.nhs.uk](http://www.nhs.uk)

The Patients Association [www.patients-association.org.uk](http://www.patients-association.org.uk)

NHS Constitution [www.dh.gov.uk/en/DH\\_113613](http://www.dh.gov.uk/en/DH_113613)

To find out more about NICE, its work and how it reaches decisions  
[www.nice.org.uk/AboutGuidance](http://www.nice.org.uk/AboutGuidance)

