What I tell my patients about ...

newly-presenting nephrotic syndrome

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British Journal of
Renal Medicine

What I tell my patients about ...

'What I tell my patients about ...' is a patient information service specifically designed for renal units to use with their patients. You can download the articles that you require for use in your unit and print them to share with your patients. If there are any particular topics that you would like to see covered in the journal, please let us know at edit@hayward.co.uk

- anti-GBM disease (or Goodpasture's disease)
- benefits and entitlements
- blood and urine tests
- clinical research
- conservative kidney management
- conservative management of their established renal failure
- contraception and pregnancy in renal disease
- contract medium toxicity
- cystinuria
- diabetes
- diabetes and their kidneys
- diet in chronic kidney disease
- encapsulating peritoneal sclerosis
- exercise
- fibrillary glomerulonephritis and immunotactoid glomerulopathy
- kidney stones
- kidney transplantation
- living kidney donation
- magnetic resonance imaging
- membranous nephropathy
- membranous nephropathy
- microscopic haematuria ('dipstick haematuria')
- MRSA infection
- obesity and renal disease
- over-the-counter medications
- pancreas transplantation
- peritoneal dialysis
- polycystic kidney disease
- preparing for haemodialysis
- reducing infection risks during haemodialysis

What do I tell my patients?

How well do I educate my patients/parents?

……I am sure others must do it better.

How am I supposed to educate my patients?

EDUCATE model for verbal education

Enhance comprehension and retention.

Deliver patient-centred education

Understand the learner

Communicate clearly & effectively

Address health literacy & cultural competences

Teaching and education goals

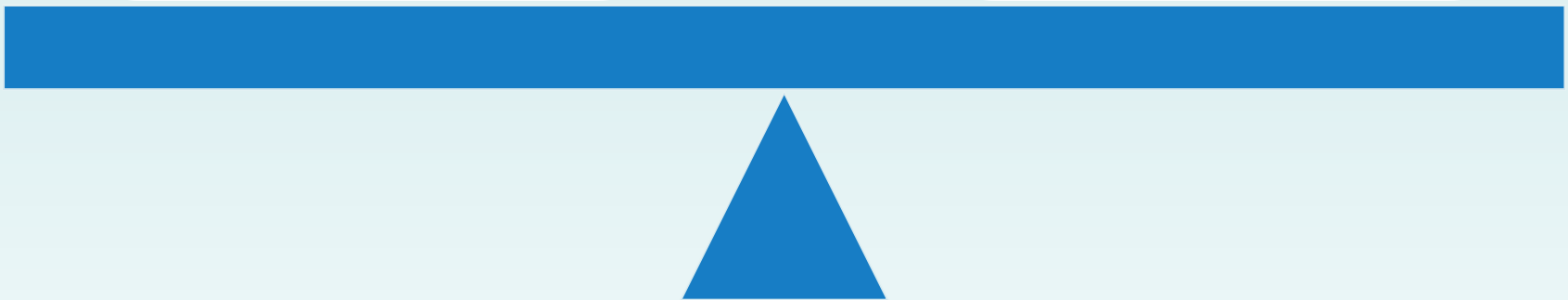
Strategies for improving the quality of verbal patient and family education: a review of the literature and creation of the EDUCATE model

Health Psychology & Behavioural Medicine 2014 Vol2 No 1 482-495

A Balanced Approach

What the parents want to know

What I think they need to know



What the parents want to know

What is wrong with my child?

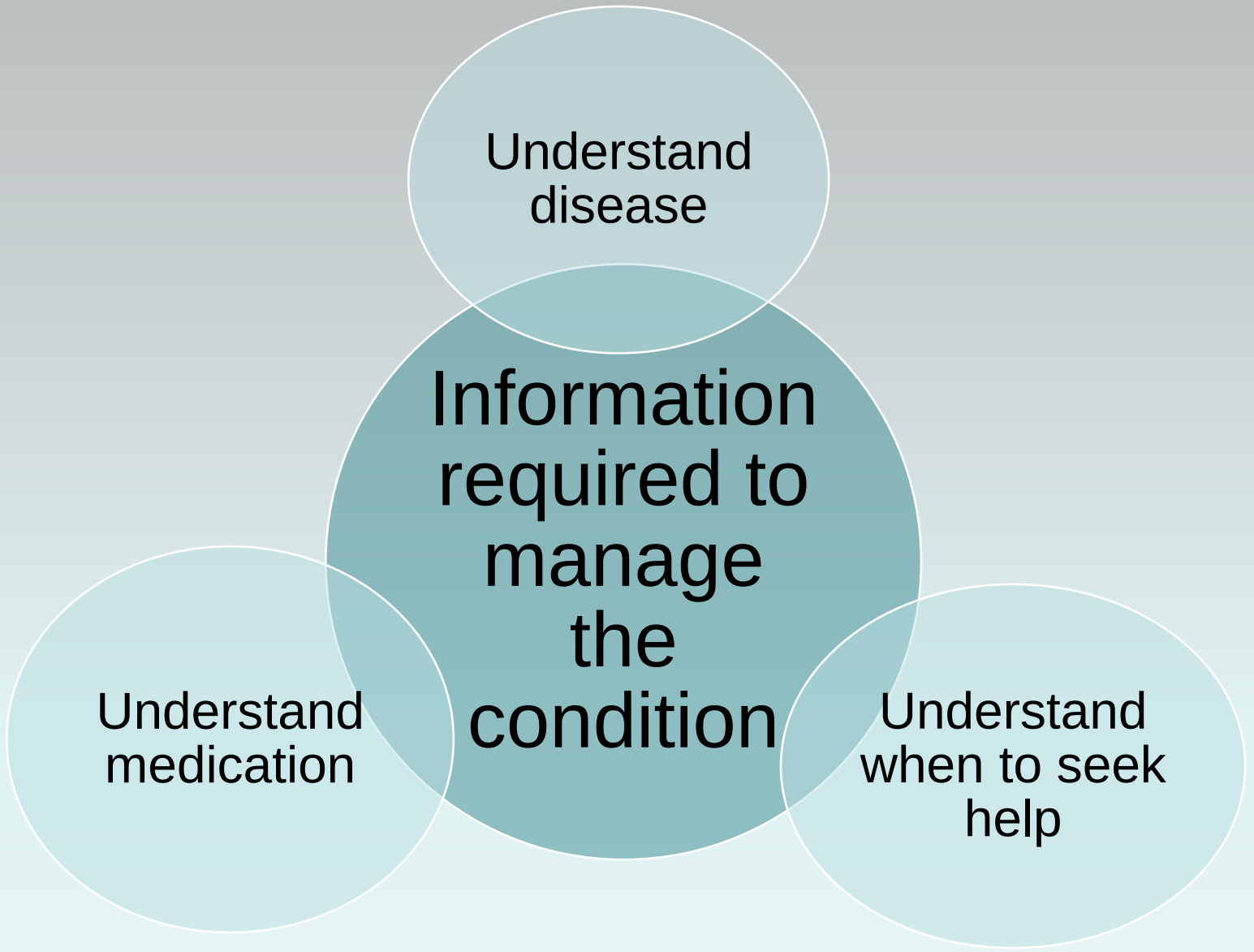
Will they get better?

How do you treat it?

How long will we be in hospital?

How has this happened?

What I think they need to know



What is Nephrotic Syndrome?

- Definition
- BASIC physiology (tailored to parent)
- Idiopathic (can even sew seeds of research)
- Need to monitor/manage the “nephrotic state”/ Risks (reason the child is going to be in hospital a few days)

Treatment

- Steroids not instant cure (work for majority of patients but take a while)
- Length of treatment expected

- Side Effects
  - Behaviour
  - Appetite
  - Immunity

Monitoring

- Relapsing and remitting condition (in the majority of cases) – what does this mean
- Why & How to dip urine
- How to record
- How to get help/ advise
- Need to attend OPD regularly

Odds and Ends

- Local experience
- Immunizations
- Chickenpox
- Long term outlook
- Involve the child

What I don’t say

- What will happen if they don’t respond.

I don’t mention biopsy or renal impairment.

What are the symptoms of childhood nephrotic syndrome?

The primary problem in childhood nephrotic syndrome is in the kidney, specifically the glomeruli, causing leakage of proteins.

This can be the result of a genetic or inherited condition where the glomeruli have not developed normally or due to an over-active immune system that is targeting both kidneys.

In the long term, if the protein leak persists this can lead to a decline in kidney function with eventual kidney failure.

Initially the symptoms are caused by the loss of proteins. Proteins have a lot of very important functions in our blood. As mentioned above, they help regulate the amount of water in our blood vessels, so with proteins lost in the urine, children with nephrotic syndrome can swell up.

Proteins have many more functions. Specialised proteins called antibodies are an important part of our immune system. If antibodies are lost, children are much more likely to get infections.

Proteins also act as carriers for many substances in the blood such as hormones and lipids. Therefore, the regulation of these substances can be disturbed in nephrotic syndrome.

Proteins are also important building blocks for our bodies in general so children with nephrotic syndrome often have difficulties in growth and development.

Finally important proteins that prevent the blood from clotting are also lost in the urine. This makes children with nephrotic syndrome more prone to blood clots.

How is childhood nephrotic syndrome diagnosed?

The initial test for nephrotic syndrome is to check the child's early morning urine (first urine sample of the day) with a dipstick. This will change colour if protein is present in his or her urine.

Blood tests will usually be needed too, both to confirm the dipstick result and to measure how well the kidneys are working to remove waste products. In some cases, a kidney biopsy may be suggested.

This is a procedure to remove a very small piece of kidney tissue to examine under a microscope. The biopsy is processed in three different ways. First of all, we look at it under a microscope. This may give us some information within a day or two. We then do special stains on the sample, which takes a bit longer, and electron microscopy, which takes longer again.

All the information gained from the urine tests, blood tests and biopsy will help identify what is causing the child's nephrotic syndrome so that the best treatment can be suggested.

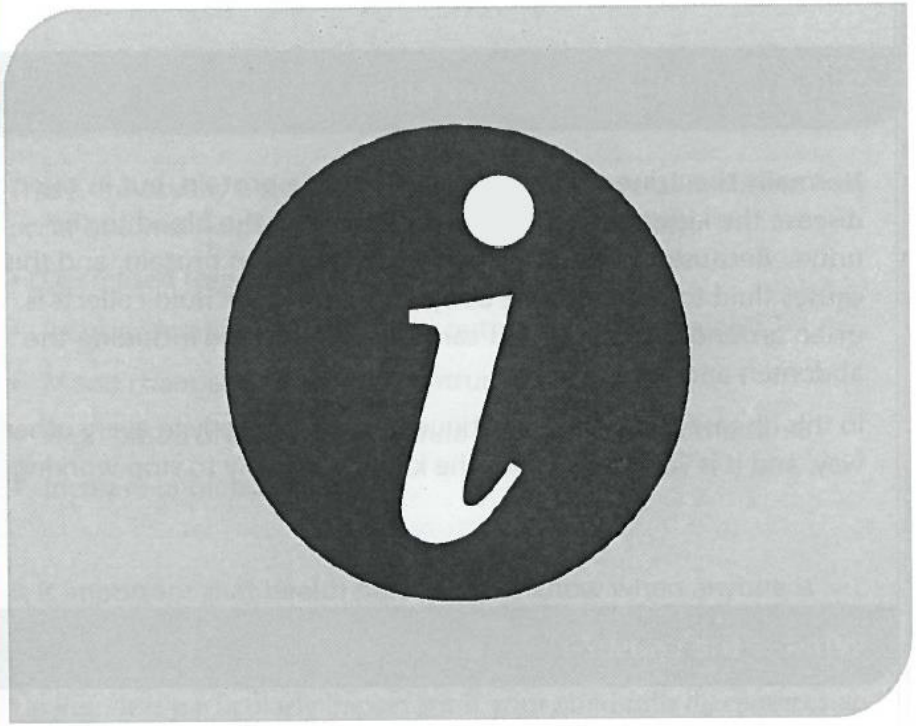
How?

- Bit size pieces
- Repetition
- Check understanding
- Appropriate to the family
- Involve others (nurses, dietician, medical students)
- Give written information
- Recommend websites

Childhood Nephrotic Syndrome

Children's Hospital

Information for Patients and Families



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childhood NEPHROTIC SYNDROME

A guide to the treatment and management of Childhood Nephrotic Syndrome

childhood NEPHROTIC SYNDROME

DIARY RECORDS

https://www.infokid.org.uk/

infoKID
Information for parents and carers about children's kidney conditions

Home Glossary About Us Contact Us

Conditions | Tests & Diagnosis | Treatment | Supporting Information | Useful Contacts

Welcome to infoKID

Providing information for parents and carers about kidney conditions in babies, children and young people.

Read about conditions, tests, treatments and supporting information - on screen or in downloadable leaflets.

An evaluation of infoKID has been completed and a report produced which outlines the findings and recommendations for future development. The report can be viewed here

Conditions

Tests and Diagnosis

Treatment

Questions

- Encourage questions
- Suggest they write down questions for next time.

Click here to view this parent interview

Useful links - EMEESY | Nest | NeST facebook nephrotic sy

https://nstrust.co.uk/

NeST NEPHROTIC SYNDROME TRUST

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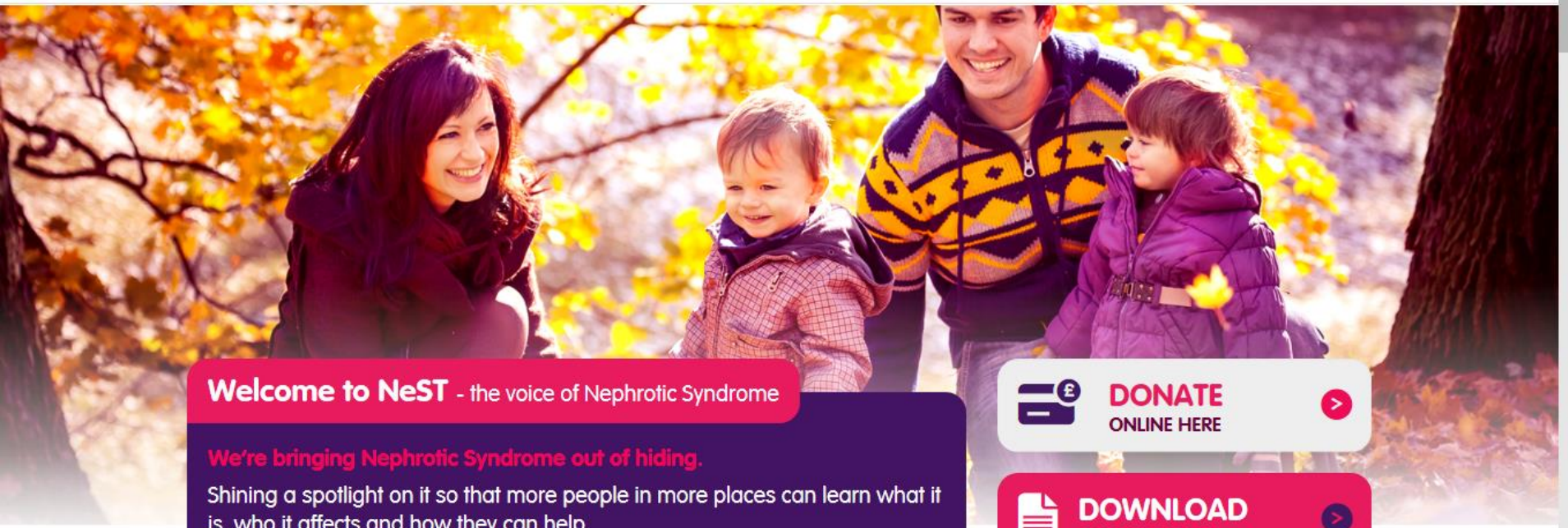

Welcome to NeST - the voice of Nephrotic Syndrome

We're bringing Nephrotic Syndrome out of hiding.

Shining a spotlight on it so that more people in more places can learn what it is, who it affects and how they can help.

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- What is it?
- Will it get better?
- How are we going to treat it?
- What effects will the treatment have?
- Will it come back?

- Notes
- Long term outlook
- Experience locally
- Immunizations and chickenpox