

Paediatric kidney conditions: Information for families User focus groups – Summary report of findings - May 2012

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Why do we need new information?

Families of infants, children and young people with kidney conditions need high quality information. Written information can offer families guidance and support in addition to that provided by their health professionals. It can tell them what they need to know about their child's condition and the treatment options. It can help them make decisions about their child's care. And, it can signpost to further support as and when they need it.

The Kidney Information Project is developing a national information resource about paediatric kidney conditions for parents and carers. This will include 50 electronic leaflets ("e-leaflets") that families will be able to access on a public website and through their health professionals. The project is run by a partnership of three organisations:

- **Royal College of Paediatrics and Child Health (RCPCH)** – represents all children's doctors
- **British Association for Paediatric Nephrology (BAPN)** – represents all children's kidney doctors (nephrologists)
- **British Kidney Patient Association (BKPA)** - improving the lives of kidney patients by giving support, information and grant aid; funding this two-year project

What did we want to find out from families?

The Kidney Information Project Board wants to make sure that the e-leaflets are high quality and meet the needs of families. RCPCH staff researched the views and perspectives of parents, carers and young people through focus groups at two paediatric nephrology units (Bristol and Birmingham).

The focus groups were mostly aimed at the key users of the information resource – parents and carers of children with kidney conditions, as well as young people with kidney conditions. We also involved young people with no experience of kidney conditions through the local Medicines for Children Research Networks (MCRNs).

The Project Board discussed and agreed what we wanted to explore in the focus groups, including:

- What is high quality, accessible, useful and relevant information
- What is bad, inaccessible or unhelpful information – what do we need to avoid
- What they need to know when their child (prenatally, infant, child or teenager) is diagnosed with a kidney condition – and at different stages of the disease
- How can written information be used during their child's journey – in clinical settings, at home – and to share with others, including extended family
- How can information be structured

Who participated in the focus groups?

A total of 27 people, including 15 parents, eight young people (two of whom were kidney patients) and four health professionals/researchers, enthusiastically participated. All provided consent for their contributions to be anonymously shared to help develop this new information resource.

What did we find out?

Below is a summary of the findings. For a more complete report (12 pages) please request a copy by emailing kidney.information@rcpch.ac.uk

Characteristics of **GOOD** information about kidney conditions

- ✓ Gives information at the right time - families need different information depending on the stage of their child's illness
- ✓ Follows on from conversations with our children's health professionals
- ✓ Is targeted to us as parents and carers (*not* health professionals) – understands our own emotional needs as caregivers
- ✓ Is detailed and explains medical terms
- ✓ Is written in a friendly tone, and easy to understand
- ✓ Gives real-life information - with a true picture of what things are like, with photographs of actual patients, quotes from actual families, and real scenarios
- ✓ Is credible, based on scientific evidence and accurate
- ✓ Sets clear expectations about disease, and helps us make informed decisions
- ✓ Gives practical information, e.g. how to take care of our children after a transplant, how to get financial support, our rights with employment for taking time off work
- ✓ Is visually appealing – using colour, bullet point lists and relevant images
- ✓ Tells you how to find more information and support, especially that is local
- ✓ Helps you communicate with others
- ✓ Is reassuring – lets us know that other families are going through this experience
- ✓ Is up-to-date

Characteristics of **BAD** information about kidney conditions

- ✗ Gives us too much information, too soon – we don't want to be overloaded
- ✗ Gives us too little information – does not answer our questions
- ✗ Gives unnecessary, unhelpful or “woolly” information
- ✗ Is not targeted at us as parents and carers, and is too complicated to understand
- ✗ Is “spin” – trying to “sell” you something, but is misleading
- ✗ Is vague or confusing
- ✗ Is hearsay – not based on evidence and inaccurate
- ✗ Contains sweeping general statements that stigmatise people

Structure (general → specific information)

1. Overview – how will this impact our child and our family?
2. Detail about condition and treatment options to access when we need it
3. Options to access more information when we need it

Content – what does the information need to answer?

When we first find out

- What is the impact on our child? Is it life threatening? Will it change the way that they live? What is their quality of life?
- When and how did they get this condition? Is it in the genes, and can it be passed on to other family members?
- How common is this – do lots of people have it, or is my child the only one?
- Can it be cured? How?
- How will they feel - will they be sick, tired, etc.?
- What are the long-term effects? Can it affect other parts of their body?

Managing a kidney condition

- What is the condition? What is wrong with their kidneys? What do kidneys do?
- What tests will they need to have, and how often? Blood and urine tests, surgery?
- How do I know when their condition is giving cause for concern?

- What does the treatment involve? How many times will we need to go to the hospital? Or can they be treated at home?
- What will the treatment achieve? Will we see a difference? What happens with other children?
- Why do some children with the same condition receive different treatments?
- Which medicines do they need to take and why? What else do I need to know?
- Do they need to change their diet?
- Will they need to be on dialysis? What happens? How do I choose the best type?
- Will they need to have a transplant? When? What happens? Can I donate a kidney?
- Are there any symptoms we should look out for?
- What happens if things take a turn for worse – e.g. when a transplant or other treatment does not work?

Living with a kidney condition

- How is this going to change my child's life? Education, sports, friends, holidays...
- How is this going to change our family's life? How do we deal with stresses and strains at home? Loneliness?
- How do I tell their siblings? Extended family?
- How can others help us?
- What and how do I tell my child's school or daycare?
- What support is available for practical, financial and emotional issues?
- Is there a contact number if I need to ask further questions?
- What information is available that I can look at in my own time when I am ready?
- Glossary of medical terms – that we can take with us to clinic

Format ideas

- Small size when printed, so it fits into our handbag or our “hospital book”
- Space for our own notes and questions for the doctor/nurse
- Other formats – like CD-ROM, talking, e-reader
- Interactive animation
- Linked to and from our hospital's website – so we know it is creditable
- Online forum for parents of children with kidney disease, based in UK

Feedback

We invited written feedback via a simple form. Comments included:

- “Really very informative session. Allowed understanding of the larger issues / concerns from young patients with kidney disease and parents / guardians, where information can be more valuable. I think the main outcome of this project will allow better overall care from health professionals and, ultimately, allow young people with kidney disease to take initiatives in their own care.”
- “Really enjoyed today, and meeting parents in the same position as myself.”
- “Enjoyed afternoon – happy to make any further contribution.”
- “Fantastic day! Couldn't have been better. Clear and great discussion and real life stories. Great presenters. Well done.”

Acknowledgments

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We are grateful to all those who joined the focus groups for giving up part of their Saturday to enthusiastically participate in the activities and share their experiences.