

The Parental View of Kidney Care

An ethnographic study into parents of young adults with kidney disease
March 2013



Kidney Care

About NHS Kidney Care

NHS Kidney Care is renowned for its expertise and experience in practical service improvement, providing leadership and resources to enable health professionals and commissioners to improve the experience and outcomes for people with kidney disease and other long-term conditions.

NHS Kidney Care was established in 2008 as a national service-improvement team. Since then, NHS Kidney Care has evolved in line with the priorities of the health service and is leading the way in supporting innovation in kidney services, identifying, sharing and supporting the implementation of new approaches that drive up quality and lead to better outcomes for patients, while securing a more efficient use of resources.

In April 2013, NHS Kidney Care became part of NHS Improving Quality, a new organisation created to bring together knowledge, expertise and experience from across the NHS, establishing a new vision and re-shaping the healthcare improvement landscape.

About Ipsos MORI

Ipsos MORI is one of the largest and best-known research companies in the UK and part of the global Ipsos Group. The Ipsos MORI Social Research Institute is the leader in public sector research, helping policy and decision-makers understand what works. Their award-winning Ethnography Centre of Excellence explores the behaviours of citizens, consumers and stakeholders to provide rich strategic insights for their clients.

© Ipsos MORI /12-064052-01
March 2013

Victoria Guyatt
Billie Ing

For further information, please contact the Ipsos Ethnography Centre of Excellence on 020 3059 5000 or email ethnography@ipsos.com.

Legal notice

© 2013 Ipsos MORI – all rights reserved.

The contents of this report constitute the sole and exclusive property of Ipsos MORI.

Ipsos MORI retains all right, title and interest, including without limitation copyright, in or to any Ipsos MORI trademarks, technologies, methodologies, products, analyses, software and know-how included or arising out of this report or used in connection with the preparation of this report. No license under any copyright is hereby granted or implied.

The contents of this report are of a commercially sensitive and confidential nature and intended solely for the review and consideration of the person or entity to which it is addressed. No other use is permitted and the addressee undertakes not to disclose all or part of this report to any third party (including but not limited, where applicable, pursuant to the Freedom of Information Act 2000) without the prior written consent of the Company Secretary of Ipsos MORI.

Contents

Foreword	1
Summary	3
Introduction	5
Background	5
Research aims	5
Research approach.....	5
Technical note	6
Family case studies	8
Barbara	8
Debbie.....	9
Annette	10
Shahnaz.....	11
Letting go	13
Continuity of care.....	17
Family dynamics	20
Managing expectations	23
The future.....	26
Reflections	28
Opportunities for solutions	31

A parental view of kidney disease: This work was carried out in accordance with the requirements of the international quality standard for Market Research, ISO 20252:2006.

Foreword

Foreword

Adolescence is a time of great change, of new-found independence and new responsibilities. It is both exciting and challenging for teenagers and their parents alike. While young adults are exploring their expanding horizons, their parents are discovering how to 'let go'.

However, for the parents of a young adult with a long term condition, it can be very difficult to reconcile the need to relinquish control with the understandable desire to continue managing and protecting their child's health.

The aim of this research was to understand and illustrate the issues that parents of young adults with kidney disease face during the transition to independent self-management and care. It has its roots in two long-standing areas of NHS Kidney Care's work.

The first has been our project to develop new ways of meeting the specific social and emotional needs of young adults with kidney disease. These individuals told us that their relationship with their parents was an important aspect of their journey to independence and self-management. At the same time, work we were doing with adult kidney patients who dialysed at home revealed the crucial role that their carers play in supporting them, and the impact of that role on the carers wellbeing.

The stories told through this research show just how important it is to work with parents as well as young adults through the transition to adult care. In the same way that young adults need support to take on their new responsibilities, their parents need support to let go. The two go hand-in-hand.

Parents make the point that age is an arbitrary measure of maturity. A period of preparation is important to ensure that a young adult has the necessary abilities and resilience to manage their own care. It also prepares the parents to relinquish control and demonstrate that they have the confidence and trust in the young adult to take responsibility for their own health, while having supportive networks in place in case they stumble.

We have begun to understand and harness the value of peer support to improve the quality of life and outcomes for people with long term conditions. In much the same way, we also need to recognise its power to support the carers of people with long term conditions. Parents need not feel like they are alone.

I would like to thank everyone who took part in this research for letting us into their families so that we can better understand and learn from their experiences. I hope that this research will help to further improve transitional support not only for young adults with long term conditions but also their families.

Beverley Matthews
Director, NHS Kidney Care

Summary

Summary

This ethnographic study explores the lives of four parents of young adults with kidney disease. As well as focusing on the difficulties they face emotionally and socially, this work looks at the information and support parents need during the crucial period in which young adults are transferring from paediatric care to adult care.

This is a particularly stressful time for parents, as the health care professionals (HCPs) and processes they have dealt with for a number of years change. Alongside this, there is also a desire by services to assist families in shifting responsibility of health management from parents to the young adults themselves. As with any form of responsibility a teenager is asked to assume, there are a number of difficulties for both parties to overcome and areas in which parents in particular are in need of further assistance and support.

This report explores the impact of kidney disease from the point of view of parents, and looks at the intricacies of their relationships with young adults. It explores 'letting go', the challenges faced during the transition to adult care, the impact kidney disease has on young adults and their families, their expectations of HCPs and the parents' thoughts on their families future.

The overall aim of this project has been to develop a guide to help clinicians support parents and families of patients with kidney disease. Based on the ethnographic interviews and follow-up interviews with three parents, this guide provides advice and recommendations for HCPs on the types of information and support parents and families would find helpful. It can be found at the end of this report.

Short films from this project were presented on 20th March 2013 at a roundtable discussion at the King's Fund in London, which culminated in a summary report articulating key challenges and potential solutions.

Introduction

Introduction

Background

The study [*Who cares for the carer?*](#) conducted by Ipsos MORI for NHS Kidney Care in 2012 highlighted that relationships between the carers and those who they care for can often be fraught. Emotions and issues such as dependency, guilt, gratitude and independence are played out alongside a chronic illness and a desire to get on with everyday life. In cases to do with parents and their teenage children, there was often a desire from parents to be overly protective and a reluctance to 'let go'.

In another 2012 study carried out by Ipsos MORI, also on behalf of NHS Kidney Care: [*Walking in their shoes: Understanding the lives of young adults with long-term conditions*](#), there was a desire from young adults to gain independence, knowing the appropriate support from friends and family was in place. A key part of this piece of work was to understand the interplay between young adults and parents and to look at the best ways for young adults to feel empowered to take responsibility.

These two research projects led to a further research question; what impact does kidney disease have on parents and the rest of the family? The following report presents the results of this question.

Research aims

The aim of this project is to illustrate the issues parents of young adults with kidney disease face during the young adults' transition to independent self-management and care, the difficulties they face emotionally and socially during this time, and to assist in identifying parents' unmet support and information needs.

Following the ethnographic interviews, each of the parents was invited to watch the edited footage and take part in a 30-minute follow-up telephone interview. The main aim of these interviews was to develop pointers and key themes for a guide to aid renal units to develop the support and information they provide to parents of 'transitioning' young adults.

Research approach

To investigate the parental view of kidney disease, we employed an ethnographic technique.

Ethnography is a method based on participant observation, meaning that the researcher is in the subject's environment, observing actual behaviour for an extended length of time, capturing all of the interactions and activities involved in daily life. Ethnography allows deep insight into the emotional nature of much of human behaviour, getting to the heart of parental and family support needs.

Ethnographic research is different to other research methods, typically using smaller sample sizes but spending longer periods of time with participants. This allows for a greater depth of knowledge - understanding the 'whys' and 'hows' in research.

A variety of sources were used to recruit participants between October 2011 and February 2013 from NHS Kidney Care re-contacts, online adverts on Facebook and Renal PatientView and the use of specialist recruitment agencies. The four ethnographic interviews were conducted across England, with a spread of ages, gender, socio-economic groups and ethnicity. The young adults in this study were also at varying stages of kidney disease, and were using a mixture of treatment options.

Recruitment to the project proved to be more challenging than expected. As such, fieldwork which was due to finish in November 2012 was extended until February 2013.

After the draft report was produced, each of the parents was invited to discuss their views on the findings during a 30-minute telephone interview. This enabled pointers and key themes to be distilled, to aid renal units in developing the support and information they provide to parents of 'transitioning' young adults.

Technical note

Researchers spent 5-6 hours with each family between December 2012 and February 2013. Details and locations are below:

Name	Location	Date of interview	Age of young adult	Modality of young adult
Barbara*	County Durham	14 th December 2012	24	Peritoneal dialysis, awaiting third transplant
Debbie*	Berkshire	25 th January 2013	21	First transplant
Annette*	Bedfordshire	8 th February 2013	19	First transplant
Shahnaz	Birmingham	18 th February 2013	16	Haemodialysis

*Follow-up telephone interviews with three of the four parents took place on Tuesday 5th March 2013.

Family case studies

Family case studies

The following section of the report provides a short summary of each family, with an accompanying filmed case study to introduce those who took part in the study.

Barbara



Barbara lives in County Durham with her children Alex and Molly. Their siblings, Jeven and Josh, live away from home at university in Newcastle. Barbara's husband works away from home in Devon. Alex, aged 24, was diagnosed with kidney failure at seven months old, having been born with the condition, and was under the care of Great Ormond Street Hospital. At the age of 17 his care was transferred to the Freeman Hospital in Newcastle. Alex, who is studying at a local college, is currently undertaking peritoneal dialysis whilst awaiting his third transplant.

Debbie



Debbie lives in Berkshire with her husband and daughter, Laura. Their son, Robert, aged 21, lives away from home at university in Surrey. Robert was diagnosed with cystinosis at birth and had to take medication to keep his kidneys functioning. During his teenage years Robert chose to stop taking his Cystagon, which subsequently led to kidney failure. Before reaching dialysis stage, in 2011, Robert's father donated a kidney. Robert is currently under the care of the young adult clinic in Oxford.

Annette



Annette lives in Bedfordshire with her daughters Emily and Georgina and husband Richard. Emily's twin sister Becky lives away from home at university. A twin-to-twin transfusion occurred just before birth; consequently Emily's blood pressure dropped, damaging her kidneys, and at three months old Emily was diagnosed with kidney disease. At seven years old, Emily's dad donated a kidney. Emily works part-time as a nursery nurse and is currently under the care of the young persons' clinic at Guy's Hospital.

Shahnaz



Shahnaz lives in Birmingham with her four children and husband. Her daughter Saira, aged 16, was diagnosed suddenly with kidney disease at the age of 11. Saira has learning difficulties, which has lowered her level of understanding; as such, her transition to adults' care will happen a year later than usual, at the age of 17. She is currently undertaking haemodialysis under the care of Birmingham Children's Hospital.

Letting go

Letting go



The following four sections of the report discuss the key themes derived from the analysis. It includes short films at the top of each section, comparing and contrasting these themes across the four families.

It's not new that young adults can cause their parents tremendous frustration. For generations parents have bemoaned the stress and fatigue caused by attempting to keep them on the 'straight and narrow'. Harvard Professor Daniel Gilbert, in his book 'Stumbling on Happiness', talks about how parents will be most "miserable" when their children are aged 12-16¹.

During these years, young adults are still changing and brain development continues until their mid-twenties, furthermore, kidney disease may delay brain development. The way in which services and parents engage with young adults needs to take this into consideration².

These years are a challenging time for parents and young people alike. It is a time for great change, greater independence and greater responsibility. Parents have to watch their children turn into young adults, and with this transition they can witness them flourishing,

¹Professor Daniel Gilbert, *Stumbling on Happiness* (Vintage, 2007)

² Personal communication, Janet Mc Donagh, March 2013

making mistakes and making life-changing decisions – education, relationships, trying drugs and alcohol and moving out of the family home are some of the issues parents may have to deal with. Add to this period a long-term condition, and it can be an especially challenging time for parents.

This piece of work concentrates on the period of time when young adults transition from paediatric care into adult services. This is typically between 16-21 years of age. As part of this move, services recognise that parents should be encouraged to start ‘letting go’ of the management and control of the young adult’s disease. This can be a difficult thing for any parent to do, let alone a parent who may have been dealing with a chronic illness for many years.

The reason for this ‘letting go’ is to encourage the young adults themselves to take responsibility for their illness, with an aim to prepare them for being an independent adult. In 2012 Ipsos MORI published a study for NHS Kidney Care: [Walking in their shoes: Understanding the lives of young adults with long-term conditions](#). This study recognised that for young adults to take on responsibility, they needed to be encouraged to engage more with their disease through empowerment. However, the complex relationship between parent and child does not always allow this to happen.

For 18 years, parents have endeavoured to normalise their children’s world as much as possible. Not making a ‘big deal’ of the disease or treating the young adult differently is especially important when siblings are present. Moreover, it is usually the parents, not the children, who have memories of what being ill means, especially if chronic kidney disease occurs at a young age. Even though they have technically been ill, in most cases the young adults themselves have always experienced what they consider to be a normal life.

Parents recognise that around the time young adults are moving from children’s to adult care they will have a love-hate relationship with their medication and that non-concordance may crop up as an issue at some point. If the young adult then becomes non-concordant with taking medication, they may not realise the implications for their health.

No matter how old children are, even if they are 18 and technically adults, some parents find it difficult to step away from providing support. This is because they may perceive that whilst they have control of the disease, the young adult has a good quality of life. When they start to hand over control, this is when problems often occur.

Having additional support during the move into adult care has proved useful. Families who have experienced renal support workers have found them extremely valuable. Young adults see them as friends (not ‘nagging parents’), and parents see them as a continued professional link to the disease they have looked after for so long, and a place they can turn to for emotional support. But support is not something parents feel they receive enough of, and a desire for more help over this period from support workers is something that Annette, Barbara and Debbie have encouraged.

Letting children do anything for the first time may entail a ‘bumpy ride’. Where health is concerned, for parents, this ‘bumpy ride’ is translated into a matter of life and death. For years, there have been arranged ‘ways of doing things’; now, to enable a young adult to take more responsibility, routines and rituals that have been in place for years have to change, and sometimes parents have to work out these new ways of doing things without outside help. Parents recognise that their children need to ‘own their disease’ and make their own decisions, whatever they may be, however, parents will avoid the avoidable if they can. As ever, parents still ‘nag’, and feel they need to, as they understand the reality of losing sight of the state of one’s health – it just can’t happen. They may find ways of checking up on the young adult, by using cues, such as checking water measuring bottles to keep an eye on a fluid restriction or making sure tablets have been taken by keeping an eye on the dosette box.

However, when major setbacks occur, parents like to regain as much of the control as possible. Shahnaz, Barbara and Debbie have all faced such instances when they have not been around to provide support. Shahnaz had to travel abroad at short notice, and during that time her daughter, who was on peritoneal dialysis, developed an infection. Debbie went away for the weekend and wasn’t there to put her son’s tablets out on the kitchen cabinet all weekend, so even though he knew where they were kept, he didn’t take them. Barbara’s son moved out of the family home and failed to manage his condition appropriately, resulting in his transplanted kidney failing. Such instances may make parents want to regain the control but in the long-term do not provide a solution to encourage the child to become an independent adult.

Continuity of care

Continuity of care



All of the parents in this study have spoken highly of the holistic care package received from paediatric units, where nurses and doctors are known on a first-name basis and almost become a part of the family. Health care professionals (HCPs) have seen the entire family through the 'ups and downs' of the first 18 years of patients' lives; they've attended birthdays, visited the family home, been there to support the parents through very stressful medical operations.

When a child transfers to the adult hospital, families feel like they have to 'start all over again'. Parents perceive that adult services assume that the young adult and family no longer need the holistic support network that's provided as part of paediatric care. Parents feel quite isolated after the care and attention from paediatrics and feel like their children have been thrown quite swiftly into the 'adult world'. It's difficult at this time to find a replacement support network, at a time when arguably they need it most.

Good friends are on hand but don't really understand what parents are going through, and the basic counselling on offer from local services is not perceived to be as useful as it could be. This is because, like with family and friends, the advice and support does not come from someone who has experienced kidney disease him or herself. Being connected to someone with similar experiences is something repeatedly requested from parents and young adults alike.

Around the same time that parents are encouraged by services to hand over management of a long-term condition to their child, services are transferring the care of the young adult from paediatrics to adult clinic care. For parents, this translates as a stage in their child's patient journey where the continual support and care from the paediatric clinicians is lost and they are dropped into a new world of HCPs, hospitals and routines. For the young person, a new adult hospital where they are now the youngest patient and are sitting in the waiting room with older kidney patients is very daunting; it feels different, familiar people are not present to comfort them, and new processes aren't explained in the way they are used to.

Alex described the transition from Great Ormond Street Hospital (GOSH) to Newcastle Hospital as being 'thrown out'. In Shahnaz's case, this is exacerbated by Saira's learning difficulties, which means her understanding of the world is limited to a younger age than she is. In all cases, parents don't feel confident in this new world, and are equally as upset at having to leave a large support network behind. With this in mind, a smooth transition is of utmost importance. There is a clear contrast between the outcomes experienced by those who were supported through transition and those who lacked support and felt 'dropped in at the deep end'.

Losing a care package that has been in place (in some instances) from the child's birth, has a tremendous impact on how well a parent feels supported. The usual set-up of an adult clinic is in complete contrast to that of a paediatric unit. Seeing different consultants on different occasions is seen by parents and young adults as a lack of continuity of care, and having to repeatedly describe the background to a child's case can have a great emotional impact on a family. Parents don't understand why only medical notes (not family history and psychological backgrounds) transition with the young adult to adult care. In some instances, where young adults have co-morbidities, there can be some confusion when conflicting messages are delivered by two different consultants.

During this time, for young adults and their parents, support from people who understand them, because they've been through a similar situation already, is of upmost importance. Connecting young adults to other young adults, and parents to parents who have been through transition, makes a big difference to how supported they feel. This reflects the findings in other patient/carer work Ipsos MORI have carried out.

Family dynamics

Family dynamics



In a family where a child has a long-term condition, however much parents strive to lessen the wider effect this has on the family, life can often be difficult. For parents whose first child is born unwell, it can be a daunting and scary start to the world of parenting. Where diagnosis occurs at a later age, and where they have siblings, life can suddenly become very different to families who are used to their children having full health. Having a child with a long-term condition changes the dynamics of the family, with parents (particularly mothers) often having to give less focus to other siblings, their partners, and themselves.

Depending on how smooth the transition to independent self-management and care has been, for siblings, having a brother or sister who has a long-term condition can be difficult. In striving to 'normalise' the life of the family, some parents see merit, where appropriate, in taking the whole family along to hospital appointments so they can understand their sibling's health. In Annette's case, her younger daughter Georgina has perceived her life as so normal that it is a shock to her friends when she now discusses her sister's condition. Debbie's daughter Laura has felt little impact of her brother's condition, citing it as something that is normal and that has always been there.

In most instances, however, giving attention and care to the child with a long-term condition is extremely demanding on parents. These demands range from spending significant periods in hospital, transporting them to appointments and dialysis, monitoring fluid intake and diet,

and worrying about test results and medical operations. Parents may perceive that time cannot be taken up with anything else, and striving for a 'normal' life is an aspiration that many feel is out of reach.

At early ages, siblings can feel like they are being left out and get frustrated with the perceived favouritism towards their brother or sister. Clinic visits can be seen as fun trips away from school that seem unfair. Because mum and dad have so little time on their hands, siblings may have to miss extra-curricular activities because their parents are tired and simply lack the time.

It can seem like the young adult with a long-term condition dominates the family; this is especially true when they are frustrated with their condition, which can translate into anger and anti-social behaviour. Often there can be embarrassment from siblings and parents at these types of behaviour, which cause tension within the family. As well as this, disruptions to the wider family routines can also occur with medical emergencies. Significant disruption can be caused to work and school routines by unplanned trips to hospital or extended periods of a sibling being unwell at home.

Respite is an issue which most of the parents in this study have struggled with. Annette and her husband didn't spend a night away from their children for eight years and Barbara feels she cannot visit her husband, who works in Devon, for fear of having to leave her son to take care of himself. In Shahnaz's case, she feels this has affected her family's health. Juggling being a housewife and taking her daughter to dialysis three times a week has left her no time to fit in things like going to the gym. Consequently, this is slowing down the treatment process for her daughter because she is the matched donor but has to lose some weight before the operation can take place.

When siblings grow older, role reversals can take place. Some siblings try to help out their parents by accompanying younger ones to appointments, and others try to include their sibling when arranging to go to social events. Although the dynamics of a family may change for the better as brothers and sisters begin to 'accept' their siblings' needs, it can sometimes be a frightening time for them as they begin to realise the full extent of what a long-term condition means for the family.

Managing expectations

Managing expectations



For up to 18 years, parents and their families have experienced holistic support from paediatric care. Without due care and consideration in the lead-up to, during, and after transition, it is not surprising that expectations of services can, in some instances fall short of reality. Where a smooth transition has taken place, expectations of parents seem to have been met.

Contradictory to the push from services for a child to become an adult and take on his or her own self-management and care, some young adults feel that clinics don't recognise that they have a life outside of the illness. In an attempt to normalise her life, for Emily, having a job and travelling 100 miles to her hospital appointments is something her employer accepts. However, Emily points out that in some cases she will receive a call the following day asking her to 'pop in' and discuss a blood result – this is where her disease starts to encroach on her life.

For parents, the sudden change to complete independent care from a clinical perspective can be a difficult step. The push from services to put the onus of managing the disease and all it entails onto the young adult can mean parents feel 'in the dark' about treatment plans. Parents have managed the disease for up to 18 years and young adults can be uncomfortable about sharing notes of their clinical discussions with their parents. During this time, parents can struggle with the tension between pushing the young adult to be independent and being a protective parent.

Moreover, the ‘total family support package’ is now gone, and families can be at a loss about where to turn for help. Barbara believes her family wouldn’t have got to ‘crisis point’ if the support system at paediatrics had followed through into adult care.

Some parents have noted that young adults have voiced concern about being pushed into making decisions in adult care that they don’t want to make without support from others. Young adults themselves have avoided telephoning for results for worry of bad news; in this case a parent is at a complete loss, as they cannot call on their child’s behalf. It has been suggested that a ‘frank conversation’ between services and young adults should be had, in order to recognise the need for support from parents, and therefore adapt consultations to suit individual circumstances.

Parents also recognise their need to be able to get to know the new clinical team and grow confidence in them. In turn, if relationships are built, then clinicians may be better prepared to be able to say, “Step back,” when necessary. Once this trust has been built and the family have confidence in their medical team, parents will feel confident the young adult will keep going to clinic and ultimately stay healthy. At this point, parents begin to feel satisfied.

The future

The future



As with the 2012 [young adults study](#), the parents in this project have varying degrees of aspiration and hope for the future. Barbara feels Alex will depend on her for the next eight years whilst her other children forge careers and start families. Shahnaz won't make plans because she doesn't know what is around the corner. Emily is happy with her job and is making plans to start studying at university, whilst Robert is an aspiring film director.

Whatever the situation, these parents will always be there for their children and imagine playing a role in the course of their condition for years to come. The degrees of 'success', to which families can look positively into the future, could be greatly increased if all members of the family felt they had a support network. The next section of this report provides conclusions and recommendations on how best to provide parents with the appropriate support and information they need.

Reflections

Reflections

In ethnographic research projects which involve discussing sensitive issues, it is important that the participants are given the chance to reflect on the findings and films before they are published.

After the thematic analysis and edits for this report had been completed, each of the four parents was given the opportunity to watch the films and take part in a 30-minute follow-up telephone call to discuss their thoughts. The ultimate aim of these follow-up interviews was to understand how renal units can provide support and information for parents during the young adults' transition to independent self-management and care.

Parents suggested that in spite of lots of literature on parenting in general, **there is little to no guidance on helping a child with a long-term condition during transition**. They feel that this report may begin a debate between health care professionals (HCPs), services, young adult patients and parents into how this gap in guidance can be addressed.

It has to be recognised that reaching a given age is an arbitrary measure of maturity. Therefore, parents suggest that **preparation should be the first step in getting a young adult ready for transition**. A troubleshooting stage six months to one year before the move to adult clinical care (which could involve running paediatric clinics as if they were adult clinics) would enable HCPs, young adults and their parents to work together in identifying unmet support needs and areas for development. This would ultimately empower young adults with the skills for what adult care could bring.

Empowering young adults to be able to ask questions and seek advice and support could be key for their future wellbeing. For a young adult arriving in a rather daunting adult clinic, asking for such help may feel counter-intuitive to the push from services for them to take on independent care and management of their health.

Parents also feel it is **important to meet with the adult clinical team ahead of the transition**. Apart from this enabling them to understand who the 'go-to' people are if they need help, it will also help them to start building a relationship with the people who are going to be taking care of their son or daughter. **Initiating a partnership between the parent and hospital** will be important in ensuring the young adult has rounded support, and for the parent it is reassuring to have confirmation that they are carrying out their role. Building confidence to feel reassured in clinical teams will help them feel better-placed to support their children through transition.

Parents would welcome a **formal handover by services**, enabling both children's and adults' hospitals, and the family, to discuss the background to the young adult's case (information which the parents and not the children may remember), agree their new roles and responsibilities, and be advised on tips and tricks for 'letting go' throughout the different stages of transition.

During such a handover meeting, an **introduction to the wider support and resources** available to families is something which both parents and young adults would like to have more help with. This is particularly important, as when a child is ill and in hospital for a longer period of time, parents can find it a struggle to cope financially.

During a smooth transition, some of the information provided in a handover may seem unnecessary, but it could be at a later date that this information is sought; future proofing it is key. One parent suggested that the most obvious place to look for information is the **hospital's website**. In this particular instance the website only provides information for the young adults, not their parents. This would be an easily accessible place to house information on the resources available, e.g. the roles of the clinical team, the responsibilities of families and clinicians, and tips and tricks for parents on 'letting go'.

It is also vital that **services work together to provide cohesive support** for the young person. Some may have to give up education, due to dialysis commitments. If then at a later stage they receive a transplant and become well enough to work, they will not have the education and skills needed to get a job, meaning they will remain dependent. To some, this seems to conflict with the drive to help young adults gain independence concerning their health.

Sharing experiences with third parties outside of the family and clinical spheres is an important piece in the support jigsaw for both the parents and young adults. Services should help enable this to happen, through parental support groups and young adults's clinics.

Parents recognise that during a young person's life there are various stages of transition: moving from primary to secondary education; moving from education to getting their first job. **Are there support options from other services that renal units could learn from?**

All the parents in this study want to relinquish control, but ultimately want their children to remain healthy.

Opportunities for solutions

Opportunities for solutions

As above, the aim of this project was to explore the experiences of parents of young adults with kidney disease as they navigate the transition process between paediatric and adult services. Based on this research and follow-up interviews with parents after they had reviewed the films of their interviews, this section provides advice and recommendations on the types of information and support parents and families would find helpful.

Parents ask for specific guidance

Although there is a lot of literature on general parenting skills, parents would like more information, support and guidance on how to deal with a transitioning adolescent who has a long-term condition.

Parents will always be parents – no matter the age of their children

Parents cannot be expected to relinquish all control by virtue of a change in age. Recognising that they will always have an opinion and interest, even if diminished, is important.

During the move from paediatrics to adult services, parents need the most support

At and around this time, parents' worlds change dramatically; this is the point they need professional assistance with the changes that are taking place, at least until they have become familiar with the new adult services routine.

Support needs to come from those who have direct experience of kidney failure, whether this is a specialist support worker, or other patients and families who have experienced kidney failure

Parents of young adults with kidney disease feel their experiences and needs are unique and find 'general support' (counselling from the GP for instance) to be of little use, as it doesn't take into consideration the multi-faceted and on-going struggle they feel they face.

Assist in connecting families with each other

Support groups, online forums and patient networks are something many parents and patients would find useful.

Support from someone outside the family is useful for both parties

Young adults often feel like their parents are 'nagging' and parents often need reassurance that 'letting go' is the right thing to do. Having 'outside' help allows both parties to change their behaviours without feeling like a 'poor parent' or a 'harassed teenager'.

The push for increased responsibility from young adults and the move to adult services all comes at once

Putting in place steps six months to a year before the transition takes place might allow patients and parents to feel more equipped once the move happens. At present, there are two very big changes taking place at once; looking towards a more staggered approach

might help to cushion this challenging period. An example of this in practice is Birmingham Children's Hospital use of Kieckhefer and Trahms³ tool to enable a gradual transition. This breaks down the steps in four stages from parents doing everything for the young adult to the young adult becoming their own supervisor with the parent acting as a consultant.

Assist in the move to self-management (where appropriate)

Dealing directly with young adults, instead of their parents, is a positive step in helping young adults realise that this is 'their disease'. Encouraging them to administer their own medication, call for test results and monitor their own diet and fluid intake are critical steps to encourage self-management.

Not all young adults are the same

Some lack the inclination or the aptitude to undertake a number of the tasks outlined above. This should be monitored on a case-by-case basis, defined by an in-depth conversation with them and their parents.

Support needs to be offered to parents and siblings, not just to patients

The impact of kidney failure on the entire family unit needs to be addressed. The effect of long-term illness on other family members has a profound and wide-spread influence.

Grow the relationship with the parents and you'll have the trust and rapport to tell parents to 'back-off'

Parents are used to having close relationships with their HCPs. They want to trust clinicians and will look to them for guidance and advice. By gaining parents' confidence, professionals will be in a better position to give advice on how they should be supporting their children.

Empower young adults

Realise that there needs to be a development stage. HCPs should help empower young adults to ask the right questions and seek support and advice during clinic visits.

Be aware that parents may have experienced some of the disease which their children may not remember

Parents feel that at transition a large amount of historic information about their case is lost. Services should recognise the need for parents to share this information with adult services prior to transition and for the new HCPs to ensure this information is distributed throughout the clinical team. Birmingham Children's Hospital encourages young adults and their parents to write their own transfer letter informing the adult team about their lives as well as the aspects of adult care they are looking forward to and are anxious about.

³ Kieckhefer GM, Trahms CM. Supporting development of children with chronic conditions: from compliance toward shared management. *Pediatric Nursing* 2000;26:354-363