NHS
Improving Quality

Parents round table discussion
WHAT WILL THE PARENTS SAY?

CONTENTS

SETTING THE SCENE

This document describes work undertaken by NHS Kidney Care around young people with kidney disease, and the issues faced by their families and carers. The emergent themes have significant alignment with current NHS Improving Quality and NHS England national programmes, including Long Term Conditions, Experience of Care, Transition from Paediatric to Adult Services and Living Longer Lives.

NHS Kidney Care closed on 1 April 2013, when NHS Improving Quality became the organisation responsible for driving improvement across the NHS in England. Hosted by NHS England, NHS Improving Quality works to provide improvement and change expertise to support improved health outcomes. It is in alignment with the needs and challenges of the NHS, bringing together and building on the wealth of knowledge, expertise and experience of all that has gone before. The legacy improvement bodies that were brought together to form NHS Improving Quality are: National Cancer Action Team, National End of Life Care Programme, NHS Diabetes and Kidney Care, NHS Improvement, and NHS Institute for Innovation and Improvement.

Prior to this, NHS Kidney Care was engaged in a number of service improvement programmes aimed at improving the transition process and experience from paediatric to adult services for young adults with kidney disease.

In 2012 Ipsos MORI was commissioned by NHS Kidney Care to carry out three ethnographic studies relating to the roles of carers, young adults and parents. The first study, *Who cares for the carer?*, highlighted the issues that may exist between the carers of people with kidney disease and those who they care for. The second report, *Walking in their shoes: Understanding the lives of young adults with long-term conditions*, involved a series of ethnographic studies providing an in-depth look at the lives of young adults with end stage kidney disease. The third study was commissioned to examine the perspective of parents[1]. This final ethnographic study highlights the impact of kidney disease from the point of view of parents, including the difficulties parents face emotionally and socially as the individual health care professionals (HCPs), health care service organisations and processes they have dealt with for a number of years change.

At the same time there is a shift in responsibility of the management of their child's care from parents to the young people themselves.

The case study in appendix 1 describes some of the issues faced by a parent of a young adult with a long term condition.

Interviews with four parents, carried out as part of the study, identified five themes that were common to all of their experiences:

- The difficulty parents face in letting go of their child and allowing them to take responsibility for their own care
- The lack of continuity of care between paediatric and adult services
- The impact on the family of being a parent of a young adult with a long-term condition
- The way that parents' expectations, as well as those of the young adult, are managed
- Concerns about the future.

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[1] NHS Kidney Care. The Parental View of Kidney Care: An ethnographic study into parents of young adults with kidney disease. March 2013. http://webarchive.nationalarchives.gov.uk/20130504185629/http://kidneycare.nhs.uk/resources/?dispFolder=458#

THE ROUND TABLE EVENT

On 20 March 2013, NHS Kidney Care hosted a round table event to discuss the key themes highlighted by the ethnographic work on the parents' experiences. Attendees were shown a number of edited film highlights from the interviews with parents, and were invited to discuss the issues that were raised with a view to identifying the barriers as well as potential solutions.

Attendees consisted of a parent representative of a young adult with a long term condition as well as HCPs from across kidney services including a renal consultant, a youth worker, renal nurse consultants and a clinical psychologist. In addition there were representatives from the voluntary sector, policy influencers and service improvement leads. The full list of attendees is provided in appendix 2.

KEY MESSAGES

- Transition can lead to parents experiencing a change in the relationship they have had with their child, and a loss of relationships with the team of HCPs who have provided care up to transition. New relationships need to be developed and nurtured.

- The time spent in transition is, on the whole, too short and often unstructured. Transition needs to start earlier and take place over two to three years, supported by a programme and regular meetings to achieve the objectives prior to transfer. The time spent in transition will help parents to build relationships and develop trust with adult services, and will also help build linkages between paediatric and adult services.

- Health and social care professionals need to provide appropriate support and information so parents feel more confident to 'let go' of their children, and allow them to develop the skills that are necessary to gain independence. In addition, parents need support in understanding the changes to confidentiality when their young person becomes an adult.

- Peer support for parents needs to be developed so that they can spend separate time with people who are going through similar experiences. Peer support is also important for the young adult themselves.

- Health care professionals in both paediatric and adult services also need to develop the skills necessary to recognise and meet the needs of parents who struggle with letting go. The HCP needs to be 'the right person for the job' rather than someone who is just interested in it.

- Not all young adults transition from paediatric departments; some present directly to adult services. This group will not have had a transition preparation and the young adult and their families may have additional support needs.

- Young adults need a flexible service designed for them that follows the transition pathway and is not based in either paediatric or adult care. Adult clinicians should meet the young people in the paediatric environment and the paediatric clinicians should then have joint clinics with the adults in the adult environment. Joint clinics should be held in both environments or separately; the service should be shared between both environments.

- The voluntary sector has a key role to play in terms of supporting the provision of timely information, counselling services, funding for youth workers and funding for outings, trips and respite services.

- Integrated transition is not routinely happening in England and requires a policy driver.

DISCUSSION

Despite isolated pockets of good practice, the lack of continuity in care for young adults moving from paediatric to adult services, as described in the video clips, was recognised by the group. In part due to the small number of young adults with kidney disease, many adult services are yet to recognise the specific needs of this group who may feel a loss of support at transfer. Currently, transition may consist of one meeting between the young adult, their parents or carers, and one or two members of each of the paediatric and adult teams. The group agreed that transition needs to start earlier and take place over a period of two to three years in order to build relationships and trust between all parties - parents, carers, young adults - as well as members of both paediatric and adult services.

Abrupt transfer can have serious consequences, such as the failure of a transplant, if the young person is not equipped with the necessary life skills to manage themselves and their condition. The ethnographic work carried out by Ipsos MORI shows that while young adults are anxious to gain independence, their parents and carers often find it difficult to let go. This two-way tug is by no means unique to parents and children with long term conditions; however the need of these young adults to carefully manage their medication, diet and lifestyle in order to control their condition often leads to further anxiety and reluctance to let go on the part of the parent. Health care professionals in both paediatric and adult services need to recognise these tensions and help to support both parents and young adults to gain the skills necessary for independence as transition approaches. Furthermore, both adult and paediatric services were highlighted as being ill-equipped to deal with the specific needs of young adults.

An unstructured and abrupt transition can also lead to a lack of trust in adult services. Parents often find it difficult to build the same relationship with members of the adult team that may have existed within paediatric services. As such, the ability of parents to trust the professionals in adult services is likely to be impaired. This is compounded by the handover being unavailable to the larger multidisciplinary team (MDT), so the staff involved with the parent and young adult will know little if anything about the individuals.

> “Paediatricians are great with young children, but not so much with young adults – paediatricians need more experience with adolescence, need to help the parent to let go, but paediatricians are not so good themselves at letting go. Paediatricians need to get involved with the adult world so that they can understand what the changes are going to be – there’s no preparation, needs to be a gradual process.”

For a parent who has been actively involved in the care of their child for many years, handing over the responsibility of care to the young person themselves and the adult service that they, the parent, have not had the opportunity to develop a relationship with, can be very difficult. The fact that parents no longer have the right to be involved in the decision making for their child can only exacerbate the anxieties that a parent may feel about letting go. Although a young adult can choose to give their parent access to confidential information, at transition a parent no longer has the right to be involved in decision making, nor take part in consultations. Health care professionals in adult services need to gain the skills to be able to provide a similar level of support to parents that they may have received in paediatric care, without breaking confidentiality. It was agreed by all that the confidentiality clause can be a barrier to integrated service delivery.

> Transition involved one meeting with two people from each centre – a lot more needs to be done. At 18 they cut you off as a parent; it's very hard when you've looked after them; someone you've cared for… consistently cared for.

However, a perceived lack of trust of adult services by paediatric services may also contribute to the lack of trust held by young adults and their parents. Having cared for the young person for many years, paediatricians and paediatric teams may think that they know best and find it hard to let go themselves.

Health care professionals, particularly those in adult services, need skills to address the needs of parents who may be feeling anxious and cut off from being involved in the care of their child. Within paediatric services parents often develop strong bonds with health professionals who they are able to contact for support and advice in dealing with their child's condition. This support is often absent in adult services, where staff may lack the skills to deal with anxious parents who they may view as difficult, leaving parents feeling isolated and bereft.

> Relationships need work, it takes a long time to build trust with new clinicians but there is also the paediatric-adult relationship… the paediatric team need to get to trust us in adult services.

Clearly, work needs to be done to develop and maintain the relationships between parents and carers, young adults, paediatric and adult services. However, building these relationship does not need to be a formal process; indeed for young adults informal meetings outside of the clinical setting may often be more appropriate.

> What are they transitioning into? Standard adult service needs to change to be a young adult service – there is an issue with small numbers, young adults are lost in a sea of services for the elderly. There needs to be a service for young adults.

Questions were also raised about the type of service that young adults are transitioned into. Adult kidney services, for example, are dominated by elderly people; as such, consideration could be given to a cross cutting young adult service that could address the needs of adolescents and young people where they can meet people of the same age. Parents and young adults should be provided with a range of choices for their care.

While some young adults enjoy and look forward to transition, others find the prospect scary and overwhelming. The appropriate timing of transition will vary depending on the individual's level of maturity. Young people mature at different ages as they go through adolescence, but a young person who has grown up with a long term condition and who may have been protected from many of life's realities may mature later than their peers. Parents are often very aware of the skills that are not yet developed in their child, so there is a need to help identify the skills a young person needs to learn; parents have a role to play here. In turn, by equipping a young person with these skills, parents may feel more confident about letting go.

> At GOSH[2] when I was there I always knew there was someone I could talk to, now I don't know who to turn to.

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[2] Great Ormond Street Hospital

> “You have to say to parents that you are accessible, that they can contact you, parents don’t want to be excluded… but it has to be the right person to do this job.”

Timing of transition may also depend on where the individual young adult is on their treatment pathway; for example if a young person is changing their treatment modality at that time, transition is likely to be inappropriate. Stability is important. The support needed for the parents and a young adult who has an unplanned requirement for renal replacement therapy will also be unique. Funding mechanisms need to be developed to support flexibility of timing the transfer of care and to allow for joint working within paediatric and adult care.

The timing of transition also needs to be considered from the perspective of the parent; some are ready to engage in transition while others are not. Some recognise the need for their child to gain independence while others, rightly or wrongly, perceive their child as ill-equipped to manage their own health.

Examples of having a ‘go between’ to support young adults were discussed; University Hospitals Birmingham NHS Foundation Trust employs a youth worker to support young people by spending time with them informally. This may include, for example, visiting young people on the wards, activity days such as going to Alton Towers and, when appropriate, home visits. The bond that develops provides support to the young adult by allowing the youth worker to act as a go between with health care professionals and, if appropriate, their parents, through having signed consent from the young adult which is reviewed every six months. Having flexibility in the system to recognise and manage these different needs could go a long way to supporting young adults and their parents through transition.

> “She may be 19 but she’s not ‘an adult’, she’s not had the life experience of others… last year she didn’t take her medication and ended up in hospital.”

> “Patients say it’s very scary… paediatric services can be sociable and fun with games, adult services are very different. Some really like transition some don’t, some say their parents get left out, many value their parents’ involvement it’s mixed.”

> “There needs to be flexibility in the way we deal with things, transition clinics, youth workers, we need to build good rapport with the young patients and the parents alike.”

MOVING FORWARD

The group was asked to consider how any of the barriers to a smooth transition could be overcome. The solutions put forward are summarised the tables below:

	SOLUTION	RESPONSIBILITY OF...
PRACTICAL SOLUTIONS	**Top ten tips** - Developing a list of top ten things that health care professional should be asking and telling parents.	Through the national Young Adults network
	Peer support - Providing platforms to develop and encourage peer support for both parents and young adults.	HCPs, Young Adult, Parents, national network
	Electronic resources - Development of platforms such as Renal PatientView for parents; raise awareness and further development of resources such as Facebook.	HCPs, voluntary sector
	Practical advice for parents - Provide practical advice for parents in the form of a guide offering clarity on what advice and support there is, as well as sign posting to reliable sources of information.	HCPs, youth workers, voluntary sector, social care
	Evidence of individual needs - Ask parents and young adults to provide a checklist of what they want when they go to adult services, in order to provide the right support for parents and the patients.	HCPs
	Pre-transition day/workshop - Host pre-transition days and workshops for parents and young adults, providing education, information, and an opportunity to meet others in similar circumstances to their own.	HCPs, youth workers, voluntary sector, social care, schools and education
	Change perceptions - Moving from paediatric to adult care is seen by many as a negative step; instead health and social care professionals can help to celebrate the move akin to graduating from secondary school to university.	Policy makers, HCPs
	Incentives - Developments of incentives such as CQUINs and best practice tariff.	Policy makers, commissioners, voluntary sector, social care

	SOLUTION	RESPONSIBILITY OF...
DEVELOP SKILLS THROUGH TRAINING AND EDUCATION	**Empower health care professionals** - Provide health care professionals with the skills they need to support parents and young adults in an area where specialists can provide advice in a secure environment.	Policy makers, HCPs, voluntary sector, commissioners
	Empower parents - Provide parents with the skills necessary to change the perception of their role and their child's and to feel safe in letting go.	HCPs, voluntary sector
	Empower young people - Provide young people with confidence and self-esteem through developing the skills necessary to take control and manage their own health and healthcare; peer support; education; care planning and the support of health and social care workers.	HCPs, youth workers, voluntary sector
	Choice - Empower parents and young adults by providing flexibility and choice about where, when and how they make the transition from paediatric to adult care.	Commissioners, HCPs, national network
	Motivational interviewing - Provide support in motivational interviewing techniques to help health care professionals support self-care	Commissioners, HCPs, voluntary sector

	SOLUTION	RESPONSIBILITY OF...
DEVELOPMENT OF KEY PERSONNEL	**Liaison officer** - Support the role of a liaison officer for parents to support the patients and work between the healthcare professionals and the parents, such as those provide by CLIC Sargent.	Voluntary sector, HCPs, commissioners
	Clinical worker specialist - Support and develop the role of clinical work specialist/key worker to act as a central player between services and ensure that appropriate support is provided for young people and their parents.	Policy makers, commissioners, HCPs, voluntary sector, social care
	Youth workers - Youth workers have a unique role to play in developing close, informal relationships with young adults and have an important role to play in helping them gain the skills necessary to manage their own condition, giving parents the confidence to let go.	Policy makers, commissioners
	Link person - Introduce a link person, potentially provided by voluntary services, to aid in sign posting to other parents and other young adults.	Commissioners, voluntary sector
	Specialist psychological support - Psychological support for parents, families and young people who struggle during transition and with adult services.	Commissioners

Finally, the group recognised that while the number of parents of young adults with kidney disease may be small, their needs are not. However, many of these needs are not unique to kidney disease. At a time when resources are scarce, health and social care professionals across all long-term conditions should look to work together to provide the expert, specialist support that parents of young adults require. Transition is well positioned in the new improvement body, NHS Improving Quality, and has already been identified as one of the main programmes of work. The legacy of this work is now reflected to Domains 2 (Long Term Conditions) and 4 (Experience of Care) in NHS Improving Quality. While the focus has previously been around disease speciality areas, commissioners and policy makers now need to look at how transition can best be done across all long-term conditions.

APPENDICES

APPENDIX 1 - CASE STUDY

From the age of five, Ebony was under the care of Great Ormond Street Hospital (GOSH), as she was born with a hole in her heart, and would sporadically turn blue. When she was 10, Ebony was diagnosed with pulmonary hypertension. The side effects of the disease (shortness of breath and tiredness) meant that she rarely attended school, and instead was cared for full-time by her mother, Shirley. Ebony subsequently had a heart and lung transplant on November 30th 2008, when she was 14 years old.

Ebony and Shirley cannot emphasise enough how good the care and support was that they received from GOSH throughout their time there, and in the run up to and following the transplantation. However their experience of transition to the adult hospital, and the care when they arrived, has been very different.

Because Ebony's condition is rare and the family lives in an isolated part of the country, they had little choice of which adult unit to transition to. Once a hospital had been decided, the transition itself consisted of one non-clinical meeting at the adult hospital, before appointments commenced.

The difference in support received from GOSH compared with the new hospital was marked. The doctors and nurses at GOSH took a holistic approach to care, looking after the entire family. There were social workers, dieticians and other support workers outside of the core medical team available to the entire family, which was completely lost after the move. Moreover, Shirley felt like she had gone from being a full-time carer of Ebony, to being completely in the dark about Ebony's treatment.

When she was 18, Ebony moved in with her father, and made little effort to stay in touch with her mother. This meant that Shirley lost the close relationship she had built up with her daughter over the years and, on a more practical level, lost her benefits too. This was a very hard change considering Shirley had built her life and home around caring for Ebony. At a similar time, Ebony had a disability assessment, which concluded that there was nothing wrong with her. This meant that Ebony lost her motability allowance and other benefits, impacting upon her independence and knocking her confidence.

On top of this, Ebony does not qualify for free prescriptions - even though her medications are keeping her alive. Last year, Ebony took an apprenticeship as an accountant, but in March 2013 was made redundant due to the amount of time she has to take off for hospital appointments and illness, further knocking her confidence.

APPENDIX 2 - LIST OF ATTENDEES

Sue Cox	Guys and St Thomas NHS Foundation Trust
Emma Coyne	Nottingham University Hospitals NHS Trust
Rachel Gair	Plymouth Hospitals NHS Trust
David Gerrett	NHS Commissioning Board (NHS England)
Paul Harden	Oxford University Hospitals NHS Trust
Shirley Hargrave	Parent representative
Helen Hoyland	NHS Kidney Care/NHS Improving Quality
Billie Ing	Ipsos MORI
Rosemary Marci	British Kidney Patient Association
Beverley Matthews (Chair)	NHS Kidney Care/NHS Improving Quality
Tracey Sinclair	Young@NKF
Grace Sweeney	NHS Kidney Care/NHS Improving Quality
Mark Thompson	University Hospital Birmingham NHS Foundation Trust
Jane Whittome	National Cancer Action Team/NHS Improving Quality

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