Patient experiences of transition between care providers

www.raredisease.org.uk
About Rare Disease UK

Rare Disease UK (RDUK) is the national alliance for people with rare diseases and all who support them. Membership is open to all and includes patients and family members living with a rare disease, patient organisations, clinicians, researchers, academics and industry. RDUK provides a unified voice for the rare disease community, capturing the experiences of patients and families and raising the profile of rare diseases across the UK.

RDUK was established, in November 2008, by Genetic Alliance UK, the national charity of over 180 patient organisations supporting all those affected by genetic conditions, following the European Commission’s Communication on Rare Diseases: Europe’s Challenges.

Subsequently RDUK has successfully campaigned for the adoption of the Council of the European Union’s Recommendation on an action in the field of rare diseases (June 2009). The Recommendation outlines how EU member states should develop and implement plans or strategies for rare diseases by the end of 2013.

Since the adoption of the Council of the European Union’s Recommendation, RDUK until November 2013 worked to ensure that the UK’s health departments acted on their obligation to develop a UK Strategy for Rare Diseases, and worked to engage with the rare disease community to shape its content. Since the publication of the UK Strategy for Rare Disease by the Department of Health in November 2013, RDUK is now focused on ensuring that the implementation of the UK Strategy is effective and accountable.

RDUK is funded by restricted grants from its industry members, details of this can be found on the RDUK website.

Download a copy of this document here: www.raredisease.org.uk/patientexperiencesoftransition.htm
Chair’s Foreword

Central to the notion of being an adult is the opportunity to take control of your life to the fullest extent possible, given your abilities, desires and the resources available to support you. This is true whether you are able bodied and fit, or affected by a rare, life limiting disease. In this latter case the manner in which medical care is provided can be a key marker in one’s progression from being a child to being an adult. The need for age appropriate services is growing rapidly as, thanks to advances in our ability to manage many conditions which until relatively recently have been lethal in childhood, the numbers of people needing adult models of care is increasing steadily. Yet as this report clearly demonstrates, the provision of well coordinated, age appropriate services for young people entering adulthood is the exception, rather than the rule. As a result individuals, families and too often, professionals too, are struggling to cope at a time which is often stressful even where there is no serious medical problem to complicate the scene further.

This report, which is only an initial investigation into this issue, has found instances of poor communication, of the transfer of care from the paediatric to the adult environment being rushed and of fragmentation between adult clinical specialties, with doctors and other medical professionals being inadequately prepared and trained to support patients with rare diseases whose needs they are unfamiliar with. As a consequence patients and their families all too often rattle around the system, receiving care which is inadequate and incomplete, sometimes to the point where avoidable harms are allowed to occur. This should not be the case. The stage by which any individual must have left the care of paediatricians and have moved into adult services is known from the day of their birth. While they may have been thought unlikely to live long enough to reach that point when they were born, with the passage of time the likelihood of them living long enough to need to transition increases as the date approaches. So there can be no excuse for not planning an effective crossover. It might be difficult, but as this report demonstrates, it is possible to do this when the condition that affects someone is not rare. Failure to do so when it is rare undermines the trust and confidence of patients and families, and creates unnecessary stress and disruption in situations where there may already be difficult emotional and physical challenges to cope with, especially when, as is all too often the case, families have had to struggle to get a diagnosis in the first place, and then to get an appropriate package of care and support put together for their child. To have to go through this all over again as adulthood is reached is simply appalling.

This has to change. This report is a call to action for the NHS and for all those other agencies, public, private and voluntary, to come together with individuals and families and make a concerted effort to make transition as smooth and purposeful as possible.

Alastair Kent OBE, Chair of Rare Disease UK
Acknowledgements

We would like to express our gratitude to all the patients, families and clinicians who took the time to speak to us. Each individual, listed in alphabetical order, below has contributed to our thinking and the direction of this report.

**Aidan** is affected by Morquio’s syndrome, a metabolic condition in which the body is missing or doesn’t have enough of a substance needed to break down long chains of sugar molecules.

**Christine’s** son is affected by tuberous sclerosis complex, a condition that can lead to growths in various organs of the body.

**Claire’s** daughter is affected by tuberous sclerosis complex, a condition that can lead to growths in various organs of the body.

**Clayton** has systemic lupus erythematosus, a condition which affects skin and joints and often also involves internal organs including the heart and kidneys.

**Debra’s** daughter is affected by factor VII deficiency, a blood disorder.

**Dr Despina Eleftheriou** is Senior Lecturer in Paediatric and Adolescent Rheumatology at the Institute of Child Health, University College London and a Consultant at Great Ormond Street Hospital.

**Harriet** is affected by Duchenne muscular dystrophy, a neuromuscular condition caused by the lack of a protein called dystrophin.

**Helen Santini** is the Juvenile Huntington’s Disease Care Adviser at the Huntington’s Disease Association.

**Jan** is affected by retroperitoneal fibrosis, a condition where inflammatory scar tissue in the back of the abdominal cavity wraps itself around blood vessels, the ureter (pipe draining the kidney) and nerves.
Jane Lodwig is the lead nurse for inherited metabolic disorders and the Alström service at University Hospitals Birmingham NHS Foundation Trust.

Dr John Ioannou is Reader and Honorary Consultant in Adolescent Rheumatology at University College London Hospitals NHS Foundation Trust, whilst also being the Academic Lead in Adolescent and Young Adult Rheumatology.

Judi Maddison is the Cystic Fibrosis Nurse Specialist at the University Hospital Southampton NHS Trust.

Kayleigh is affected by cystic fibrosis, a genetic condition in which the lungs and digestive system become clogged with thick sticky mucus.

Lucy Wedderburn is Professor of Paediatric Rheumatology at the Institute of Child Health, University College London and a Consultant at Great Ormond Street Hospital.

Dr Pavel Kotoucek is a Consultant Haematologist at Homerton University Hospital NHS Foundation Trust.

Roanna is affected by thalassaemia, a blood disorder.

Sarah Borrows is the Clinical Nurse Specialist in Renal Genetics and Queen Elizabeth Hospital Birmingham.

Shelly’s daughter is affected by idiopathic intracranial hypertension, a neurological condition of unknown cause defined by increased intracranial pressure around the brain.

Toni’s late husband was affected by frontotemporal dementia, a condition that is caused by loss of brain cells in the frontal and temporal lobes of the brain.
Introduction

In November 2013, RDUK welcomed the first UK Strategy for Rare Diseases. The Strategy, published by the Department of Health in England, contains 51 commitments to ensure that health and social care systems across the four nations provide those living with rare conditions with the highest possible quality of evidence-based care and treatment. There are, however, few provisions in the UK Strategy for Rare Diseases for patients with a rare condition who will transition between care providers.

Advances in science and medicine have led to better health outcomes for patients living with a rare condition. Patients who previously would not have survived childhood are now living on into adulthood, a fact which should be celebrated. Better treatments mean that patients affected by rare diseases will be requiring a transition plan for the first time and the challenge now will be for healthcare systems in the four nations to develop age appropriate services for these patients.

In light of this, we undertook a study to gain a better understanding of the issues faced by patients transitioning both from child to adult care and from adult to older age care. This summer we spoke to patients affected by rare conditions and their families from across the UK about their experiences of transition between care providers. This included patients and families with experience of transition between paediatric and adult services, as well as a small number of patients who have experienced transition from adult into older age care and also from older age into end of life care.

RDUK also interviewed healthcare providers who have experience of managing the transition of patients with rare conditions between services. Interviews were conducted both in person and on the telephone.

The NHS is capable of providing a world-class service to families with rare diseases and many patients are very happy with the support they receive. The clinicians we spoke to are not just pioneers in the UK but also the world. Unfortunately, this high quality care is not universal to all patients with rare conditions going through transition within the NHS. Unsurprisingly, our study found that transition is better for those affected by more common conditions.

Our findings are just the tip of an iceberg; there is much more that still remains to be discovered, understood and acted upon. RDUK is committed to undertaking a further, in-depth analysis of transition from child to adult care and from adult into older age and end of life care.

The need for high quality care for patients during transition is greater than ever and the demand will only continue to increase. Now is time for action to be taken so that effective transition for people with rare diseases is provided in a coordinated, appropriate and cost-effective way.
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Good communication and coordination are essential for successful transition

People affected by rare conditions often have to see many different specialists who can be located across different departments and treatment centres. Patients and carers told us that communication between different healthcare providers is not always consistent. This is a known barrier to receiving high-quality care for many patients with rare conditions but is further exacerbated during periods of transition, especially from paediatric to adult services. As a result, parents and carers often have to shoulder the responsibility of coordinating their child or loved one’s care during transition.

Claire’s daughter is affected by tuberous sclerosis complex and her healthcare is delivered between their local hospital and a specialist clinic. When Claire’s daughter was transferred from paediatric to adult services, Claire had to take on the role of coordinating her daughter’s care as no handover had occurred between the two clinical teams. Even after the transition had occurred, the consultants at the specialist clinic were not always copied into relevant letters from the local hospital regarding her daughter’s care.

“It was a bit hit-and-miss really. The paediatric team just referred her up to their adult team and initially I thought it was going to go really smoothly but then it turned out that the paediatric team didn’t hand over properly. We had some issues when she was ill because they said they didn’t realise that she had a lot of problems and again, I had to explain everything from the beginning. We had a lot of apologies in the end from the paediatric team saying that they should have done a proper handover but the adult and paediatric teams actually work together, so the fact that the handover wasn’t done properly was just really quite frustrating for me. Even now I have to photocopy all the letters and take them to the specialist clinic. I end up having to send emails to the nurse to make sure that they’ve got everything up-to-date as it doesn’t happen automatically I constantly feel like I need to tell everybody everything and I worry about what might happen if I’m on holiday and my daughter were to fall ill? Having someone that would be able to explain everything properly would be good. It’s quite worrying at times.” – Claire

Christine has a son who is also affected by tuberous sclerosis complex and his care is delivered by a specialist clinic with which she is satisfied but she feels that there is a lack of communication between agencies.

“I don’t think there’s any liaising at all. You start to think to yourself about what happens when he does his next transition and that will be to live away from home. For us that is the really scary bit from the social point-of-view and also from the care point-of-view. It’s really frightening.” – Christine

Shelly’s daughter is affected by idiopathic intracranial hypertension, as well as epilepsy, irritable bowel syndrome and autism. Shelly’s daughter’s condition means that she is seen by clinical teams in neurology, neurosurgery and ophthalmology.
“One thing that did concern me when she transitioned over to adult services was the lack of communication between different departments but I quickly sorted that out because at appointments I’d ask them to copy certain doctors into all correspondence. So I did that with each three departments so for now, everyone is getting copied into letters from everyone. But that was me who initiated that.” – Shelly

These findings articulate the central importance of good communication for the delivery of effective joined-up care and correlate with the results of our survey on Centres of Excellence (2013). We asked members about communication between their Centre of Excellence and local hospital and just 28% of respondents said this was either ‘excellent’ or ‘works well’. Almost 40% of people who completed our survey described this communication as ‘non-existent’ or ‘needs improving’.

Patients and families feel disconnected from the transition process

Having an open and transparent transition process was welcomed by the patients, families and carers we spoke to. In particular, patients and families told us that they wanted to be involved in decisions about when the time was right for them or their loved one to transition, rather than this being the choice of a clinician speaking on their behalf.

When the time came for Claire’s daughter to transition between services, she felt that they were excluded from the decision-making process.

“Well nobody really had a conversation with us that she would be transitioning up to adult care, it just sort of was just mainly visits with consultants who’d say ‘oh she’s turning 18 soon, we’d better see who we can refer her to,’ so nobody really ever sat us down and said ‘right you’re going to go on to the next phase.’” – Claire

Where patients and parents were included in discussions about when to transition, they felt more comfortable with the process and more confident about the outcome of transition. Shelly had excellent communication links with her daughter’s paediatrician, who coordinated the transition process. She was able to contact him by telephone or email to ask questions whenever they arose and the transition process was discussed in advance of it happening with both Shelly and her daughter.

“It was at the May 2011 appointment where her paediatric consultant suggested that she had an MRI to check for a Chiari malformation as he thought that’s what her symptoms might be. It was at that point that he said depending what the results would be from the MRI, if she did have a Chiari then it would be better to transfer her over to adult services so that she could begin any treatment under adult services, rather than start it under paediatric and then half way through have to transfer once she reached 18. So that’s what prompted it at that time and he discussed it with both me and my daughter and we all agreed that yes, that was the way to go and that’s what happened and it actually worked out very, very well.” – Shelly
A dedicated transition service for patients with inherited metabolic disorders

Jane Lodwig is trained in both paediatric and adult nursing. She is the lead nurse for inherited metabolic disorders and the Alström service at University Hospitals Birmingham NHS Foundation Trust and has also been involved with home visits and care, giving her an all round view of different aspects of transition. She is now on a one year secondment project managing the Centre for Rare Diseases at Queen Elizabeth Hospital Birmingham. She told RDUK about a dedicated transition service for patients with inherited metabolic disorders that was established as a joint venture between Birmingham Children’s Hospital and the Queen Elizabeth Hospital Birmingham with consultants, nurses, dieticians and other health professionals.

"The transition service for patients with inherited metabolic disorders began approximately five years ago and we now have an established system in operation. It’s not perfect but it’s a good system where from the age of 12 to 14, patients are prepared by their paediatric healthcare professionals. We, on the adult side of things don’t get involved but the patients are prepared for transition – they know what’s happening and the process is explained to them. With complex and rare conditions there is often a high level of anxiety from parents and families about the idea of losing everything that they’ve worked so hard to get to support them, which is why I think it’s really important to try and manage expectations at that point.

From ages 14 to 16 we have joint clinics where the adult staff go over to the children’s hospital to designated transition clinics and we are introduced to the patients and their parents and are available to ask any questions. We hand over a leaflet and we are really there to sit in the background and say hello. That is quite a fluid process – one of the issues is that compliance and attendance at clinics falls off at that age and one of the disappointments of the process is not being able to get everybody there who could benefit from being there. One of the things that really influences that is the use of dedicated transition workers.

When I’ve seen in other service where they’ve used social workers or youth workers – they actually are just working with transition patients and families and able to go out to schools and colleges, work with families and support changeovers – that’s when transition really works. When this Transition service had a dedicated Transition nurse she would phone all of the families before clinic and they would know they were coming and they’d all have a reminder and they might have an agenda and she’d done some work with them and they might actually have questions to bring to clinic. That actually really heightened engagement and really helped with lowering the rate of people who do not attend. That’s quite anecdotal but the use of dedicated transition workers is really important and does make a difference.

So between 14 and 16 the adult staff would go over to the children’s hospital and at a convenient point – when the young person was ready and this would be negotiated – they would come over to the adult hospital. They can’t do that before the age of 16 but it can be at any point between 16 and 18. Then the paediatric staff will join them in their adult clinics until it is felt by the health professionals and negotiated with the young person that they are ready to leave the children’s hospital behind and move to an adult clinic. Again, this can be fluid and is done when the young person feels that they are ready. For some, it may be 16... others may stay in transition clinics beyond the age of 18. Overall, it is a system that works for many families but not all. Some need much more input than this, mostly probably outside of their immediate healthcare needs. For example, access to work, benefits, education and an absence of this support can impact on their overall health and
Our experience of transition is that it can be a really positive experience for some individuals and families and we certainly have had scenarios where families felt that they had access to far more support in adult care than they had been able to access previously, such as more generous allowances/benefits for carers in some circumstances. One of the problems is that this is not universal and the health and social care systems are not easily negotiated or accessed. Effective transition needs time and expertise in order to assist patients and families in negotiating the options available to them.

Age-appropriate services are not always available to patients

Patients told us that clinical consultations often focus on the clinical and physical needs of the patient, which doesn’t give them the chance to voice their concerns and put in place a plan for transition that takes into account other issues of importance to them.

“The thing is that at that age you’re not really a child and you’re not really an adult.” – Harriet

In some cases, the lack of an appropriate service for adolescents means that patients are being forced to transition into adult services earlier than they should be. Patients and their families were particularly concerned that necessity is often the trigger for transition rather that it being what was best for the patient.

Debra’s daughter has haemophilia. A lack of appropriate services for managing adolescents with this condition means that her daughter has had to transition prematurely to adult services for some of her care, while still being treated as a child in a different hospital.

“She’s only 14 at the moment. The problems that we’re having is that she’s a 14-year-old girl and she’s still under paediatrics really but because she’s having gynaecological problems we’re kind of going into adult gynaecological departments which is then a problem because if she needs anything doing like scans or anything then she’s being sent back to paediatrics, which is at a different hospital. So we’re between two of them really but only moved over to adults because of this problem.” – Debra

Jane describes some social factors which she believes are important issues facing many families who have children or young adults affected by rare conditions.

“One of the things that people often used to say to me was that they never expected their son or daughter to survive and become an adult and because of this they never expected to have to deal with issues such as puberty, becoming independent and personal wishes.” – Jane
Patients also told us that there is a gap in care facilities available to adolescents who transition between paediatric and adult care. They felt that services that are tailored to young people undergoing transition between a paediatric and adult care setting should be established as the services currently available for this age group are inappropriate for their specific needs and preferences.

Helen Santini is the Juvenile Huntington’s Disease Care Adviser at the Huntington’s Disease Association. Huntington’s Disease damages some of the nerve cells in the brain, causing deterioration and a gradual loss of function in these areas of the brain. This can affect movement, cognition (perception, awareness, thinking, judgement) and behaviour.

“I think there are often college courses and things that can be appropriate and you can often find something suitable when someone is 18 which can keep you going a little bit longer but at some point that facility ends and people are no longer able to access that anymore. I think that tends to happen around 21 and then for a 21 year old to be in a day centre with a group of people who are more elderly often isn’t appropriate.” – Helen

Christine was involved in the establishment of a day centre for young people with complex needs, after her and a group of parents in the same situation realised that the facilities their children needed didn’t exist in their local area. The Next Step Trust, a registered charity, now has 36 fulltime members of staff and is spread across three sites.

“One day my son was a school boy, the next he was retired with absolutely nothing to fill his days, it was a bit like falling off the edge of a cliff.”

“We were very concerned by the lack of quality adult provision when our sons and daughters left school at 19, at transition into adult services, so ourselves and a group of other parents worked together and set up a day service provision that would meet the needs of people with more complex problems. The objectives were straight forward: to provide a safe, healthy and stimulating environment to support the development of an individual’s independence and potential. Originally the service was to end at 25 but we very quickly realised that after that there was nothing to fill the void. So we decided there would be no upper age limit and that if the young person was happy and making progress, however small the steps, they could continue attending. A number of people have moved on, some having gained skills that have enable them to move to provisions more suitable for them. And of course this is what we want to happen.

But the service is dependent on the funding streams continuing and this of course is the great concern for everyone.” – Christine
Medical professionals receive insufficient training in adolescent care and medicine

Young people have differing needs to those of children and adults. Some conditions only develop during adolescence whilst other conditions present themselves in a clinically distinct manner during adolescence, yet the NHS does not make provision for adolescent medicine. As a result, there is a lack of specialists who are able to meet the needs of young people, which is especially acute for young people affected by rare conditions.

Lucy Wedderburn is Professor of Paediatric Rheumatology at the Institute of Child Health, University College London and a Consultant at Great Ormond Street Hospital.

“Who wants to transition to someone who’s never seen a case of your very rare condition before?”

“We’ve made big efforts to make sure that adult trainees in arthritis get a bit of training about juvenile arthritis and what it’s like to be aged 20 with juvenile arthritis. There are lots of issues when you’re that age with arthritis that are very different to the older age groups. But it’s all the harder to do that for rare diseases because there aren’t that many cases.

“Adolescent medicine needs to be recognised. Patients with rare diseases in particular have a great need at that age because there aren’t many specialists who will know about their disease. With increasing survival of some of these conditions it’s often only paediatricians that have experienced them. I think that’s one reason but another is probably historical – there’s paediatric medicine and there’s adult medicine and you train in one or the other so not so many people are trained specifically in adolescent medicine.” – Professor Lucy Wedderburn

Dr John Ioannou is Reader and Honorary Consultant in Adolescent Rheumatology at University College London Hospitals NHS Foundation Trust, whilst also being the Academic Lead in Adolescent and Young Adult Rheumatology.

The lack of training in adolescent medicine and provision for patients in this age group means that clinicians have to partner with colleagues in adult and paediatric medicine to share skills, expertise and knowledge, whilst also trying to develop a service to that meets the needs of young people.

“I’ve been engaged with adolescent care and partnered with paediatric colleagues to help create this pathway of both clinical care and research through the centre. I think what you need is partnerships but there’s very little incentive within the NHS to create that.” – Dr John Ioannou
Research studies are not compatible with the transition process

Adolescence is a time of significant change in terms of physical, emotional and educational development, yet it is in this age group that the least amount of medical research is performed. Clinical trials have often overlooked teenagers and as a result, treatments for young people are based on research carried out on adults and children. Research is vital for understanding how and why diseases develop and progress. This has the potential to lead to the discovery of new or better medicines and treatments, tests that will improve our understanding of a condition as well as methods to prevent complications. Patients with rare conditions are particularly eager to take part in research studies but this is currently incompatible with how transition between services is managed.

The Centre for Adolescent Rheumatology was established in November 2012 as a research initiative spanning two age groups and two hospitals: Great Ormond Street Hospital and University College Hospital. The Centre’s mission is to improve the health and wellbeing of adolescents by undertaking cutting edge research and ensuring that adolescent patients have the opportunity to be directly involved in research and clinical trials for their condition.

“Research used to be a cause for delaying transition. For example, previously children and young people with juvenile dermatomyositis, a rare disease, transitioned too late because they were involved in research studies under paediatric services but there was no equivalent study taking place in adult services. Now we’re doing better because we have colleagues to help us with the research on the adolescent side.” – Professor Lucy Wedderburn

“It’s getting a lot better. Before we had all of this organised, it was significantly later. It has improved transition for patients who are now looked after within a dedicated adolescent rheumatology unit and within that, research is firmly embedded and we are contributing data to national cohort studies for example, for many different diseases. And then there’s a second stage of transition at UCH, so patients transition from the adolescent unit to a young adult clinical service that we’ve developed there, and we continue to keep them engaged with research so they’re contributing adult data and therefore long term outcome measures.” – Dr John Ioannou

“You don’t want to lose patients from research studies and if there’s nobody in the next age group picking that up it’s difficult to transition. So now, we’re incredibly lucky because the Centre actually interweaves research with the clinical route and pathway very closely. Now when we clinically want to transition a patient with a rare disease, there are people who are very committed and involved in the research to take on those patients; it means that the research and care fit together seamlessly.” – Professor Lucy Wedderburn
Clayton’s story

Clayton was diagnosed with systemic lupus erythematosus (SLE) when he was ten-years-old, in November 2005. He was seen at Great Ormond Street Hospital (GOSH) until he was around 14-years-old when he was transferred to the Centre for Adolescent Rheumatology at University College Hospital (UCH).

“I was quite mature and because my condition was stable the team at GOSH decided to move me at a younger age to what they normally do. A couple of months before I transitioned I met with a nurse, Nicola, who works at both GOSH and UCH. I got to know her and then she was with me through the transition process.

It was good because UCH had already had a lot of contact with my nurse and she’d been in all of my meetings with me that led up to the transition. That meant she was already familiar with my condition and also with myself as a person, which is important because my condition is a very individual disease. A lot of people deal with it differently and have a lot of different symptoms so this is the kind of condition that you have to treat personally rather than generally. Nicola knew how my condition affects me personally so it was really good to have her at UCH when I arrived there.

When I was transferred to the adolescent’s clinic at UCH I much preferred the atmosphere. In the waiting rooms at GOSH you’d be surrounded by other patients ranging from toddlers and babies up to kids that were about ten-years-old whereas at UCH it was a much older atmosphere. There were a lot more people of my own age and it made me feel a lot more comfortable instead of being the oldest one in the waiting room.

Another thing that happened when I moved to UCH was that my Mum started coming less and less often with me to the appointments. When I was seen at GOSH my Mum was more involved with making the decisions – I mean, of course it’s my health and I have a say in it but she was there with me by my side but as I moved to UCH I took more control and going on my own meant that I had to grow up and get used to it.

By far the most important and helpful thing that I have had in my healthcare since I was diagnosed was having a nurse that essentially transitioned with me. At the time of the transition, if something did happen I could always contact her straight away either by her work office landline or even her mobile – I could always get hold of her.

I found the bridge between child care and adult care really useful and I think the adolescent centre is really good because otherwise that is basically like going from a paediatric ward to a geriatric ward. That transition stage in the middle where you’re surrounded by people your own age, some people going into adulthood and some coming out of childhood allows it to progress smoothly and I think that’s a really good idea and I am really supportive of it.”
Transition can come as a shock to patients and be too sudden

It was felt by many patients and carers that the transition between paediatric and adult services can occur too suddenly and sometimes even without warning. There was agreement that programmes or facilities that aid a more gradual process of transition would be preferred by patients and their families, with some patients having the benefit of being able to speak from personal experience. For those whose experience of transition had been abrupt, they felt that a more staged approach would have avoided what otherwise felt like a disconcerting step-change in their healthcare provision that was difficult for themselves and their family to adapt to.

Harriet has Duchenne muscular dystrophy and made her transition from paediatric services to adult services in 2009. The process was not planned with her and she was not properly informed about what would happen and when.

“It was basically just a conversation with the person who was in charge of child services saying that they’d like me to take the step up to adult services. I don’t really think there was a transition process at all; it was more just like being handed off to adult services. I didn’t even get any information. Meeting the adult team was a totally new experience and I think it would have been nice to meet who I was going to beforehand and to have had a conversation with who had been seeing me from the paediatric point-of-view.” – Harriet

Kayleigh has cystic fibrosis and transitioned from paediatric to adult services after being able to attend an evening clinic for adolescents that allowed her to get familiar with her new treatment centre and team.

“The idea of being moved from child to adult care was slowly introduced and there was the opportunity to meet some of the team at the adult centre and look around the centre. Getting to go there and meeting staff ahead of moving across is a good idea and because of this I think I had quite a good experience of transitioning really.” – Kayleigh

Many patients told us how the atmosphere of their consultations changed when they transitioned from child services to adult services and said that clinicians began addressing them rather than their parents. This is one example of a significant shift in how an individual’s healthcare is provided that can be difficult to get used to and can, at first, be disconcerting and challenging.

“I noticed how different it was because when you’re a child they’re a lot more thorough with you and take the time to explain things and they’re more smiley but then on my first appointment in adult care I thought ‘oh dear’ and I was being treated like an adult.” – Harriet
Aidan lives in Northern Ireland. He is affected by Morquio’s syndrome and made the transition between paediatric and adult services when he was 17.

“It was quite weird because my Mum always did the talking, you know because that’s just the way it was when you’re a child. Even as I grew up she would have done the talking because she’s able to explain things better than me but once I was in adult care they didn’t really bother with her. They were classing me as an adult and so they were talking to me rather than talking to my mother. I had to start thinking about what I needed or what I wanted and that was quite good for me.” – Aidan

Active engagement with patients rather than their parents encourages young people to become independent and gain the necessary knowledge, skills and confidence required to manage their own condition. Having a gradual programme or an adolescent clinic can help patients to prepare for how to start managing their own condition.

“The consultation was more about me and not about my parents leading it anymore, which I think was really helpful. The nurses would say things like, ‘what medication do you take?’ and you would be expected to know what medications you take and what dose and things. At 18 I was pretty independent anyway and I was going off to university but it was good to know those types of things and be responsible for managing my cystic fibrosis.” – Kayleigh

Parents feel anxious and unsupported during transition

Knowing that the hospital, clinician and specialist team that you have been working effectively with is soon to change can be unsettling for the patient as well as their parents, family and carers. This may be the case particularly if you have been receiving care from the same team over many years or have finally got used to a team after a long period of time feeling lost in the healthcare system. As a result many of the parents and families we spoke to told us that they had felt anxious and worried about their child’s transition.

Debra’s daughter is still seen under paediatric services for most of her care but one element of her care is provided by adult services, as no service exists in the paediatric department. Her daughter will soon need to complete her transition fully into adult care.

“I’m feeling very nervous about the transition at the moment.” – Debra
A cystic fibrosis centre at Landock Hospital in Wales has recently implemented an initiative which helps to address this issue by holding evening sessions for parents of children who are about to make the transition from paediatric to adult services.

“The parents come over and see the facilities as well as meeting the new adult team so that they also feel part of the transition process. Although the person needs to be independent I think it is important for the families to feel a bit more included.” – Kayleigh

Having systems like this in place can help to address parent and patient anxiety and also ensures that parents have all the information they need to help their son or daughter become more independent so they can start managing their condition themselves and feel confident about the transition process.
Ready, Steady, Go! A new framework for transition

Judi Maddison is a Paediatric Cystic Fibrosis Nurse Specialist at the University Hospital Southampton NHS Foundation Trust. Along with her colleagues, Judi pioneered a new generic programme for transition that works for both patients with rare conditions and those with more common conditions.

The Ready, Steady, Go! programme is for patients over 11-years-old with a long-term medical condition and is designed to help them and their families feel confident about the move to adult services. Ready, Steady, Go! happens in three stages and asks both young people and their parents a series of questions to ensure transition is appropriate and carried out effectively. The programme is used at the University Hospital of Southampton and has been adopted by many other services throughout the UK.

There were four or five trials of the Ready, Steady, Go! programme and young people were consulted during the development of the document to ensure it was fit-for-purpose, Judi explains.

“The feedback from the teenagers was really useful. One of the things that they liked was the colour scheme because they could instantly understand it and it meant that they saw transition as a gradual thing.”

Judi explains and how the programme works for patients and their families:

“We start them at 11, so when the children go to secondary school. The reason Ready, Steady, Go! starts at secondary school is that parents are in the frame of mind then to be thinking about their child growing up. So it seems a good point to start saying to them that their child is growing up and their adult care is now on the horizon. We start it very gently at 11, introducing the first programme ‘Getting Ready’. Initially we give the young people and their parents an information leaflet explaining the programme and a questionnaire to complete.

We then let the young people decide whether they want to fill it in with us in the room, whether they want to read it quietly and then come back to us, or whether they want us to read the document to them and then answer the questions - it’s entirely up to them. We start with the first question, which asks about their condition. From their answer we can get a very good idea of how much the child has been told already, what level they’re ready to work at and so on. We do get some surprises so we let young people work at the pace they want to. We often find that the kids that want to fill it in on their own will then drop you something big. So we’ve found that the young people who read it alone and see questions about bullying and so on, are then the ones that will often then say to you actually, ‘I’ve got a problem’ or ‘something is going on.’”

Ready, Steady, Go! incorporates aspects outside of health, which has helped to identify and tackle issues that can affect health and wellbeing.

“We put in all the other areas outside of healthcare, because they don’t just grow up with their health condition, all those other things are actually really important. One of the things we will very often see is children who aren’t being compliant with treatment and there’s often an underlining reason for that, such as bullying. We’ve had a few instances with that; children aren’t compliant because if they don’t take their medication and therefore aren’t well enough to go to school, they can avoid the bullying. So in this instance, something outside of their health is having a direct effect on their health.
In these cases we would talk to the child about what is going on and then we can advise the parents or sit down with them and discuss the options they’ve got. If you’ve got a child who is unhappy, generally is worrying and so on, it will affect their health. We are also very fortunate that we have psychology attached to the programme, so we can say to our psychologist, ‘this child is having a problem with this’ and they can then do some work with them in terms of looking at coping strategies and emotional support.”

Parents are also involved in the programme and there are specific questions for them to think about too:

“The parents are always informed with the programme because there are some issues within it of a more sensitive nature; the questionnaire for patients does mention sexual health and things like that. So we tell parents that we wouldn’t do anything beyond what is normal sex education for whatever level their child is at in school. So we always try to make sure that it’s geared to whatever level is appropriate and we always ask parents beforehand whether they have given permission for their child to undertake sex education at school. If they haven’t then obviously we have to talk to the parents first before we then pursue that issue with the child. Saying that, if a child asks us directly about sex then we’ll talk to them about it. It’s only that we can’t instigate those conversations.”

**Implementation of Ready, Steady, Go! has been challenging at times, Judi explains:**

“Education-wise it has been difficult trying to get it into every service, some are better at it than others but it does need the whole team to be engaged because it isn’t just something that either the nurses do or the doctor does, it should be any healthcare professional that sees that child for any reason.

Lots of the young people see lots of different people and it’s important they’ve got something that is actually written down so that everybody is saying the same thing to them, or if something changes that can be documented.”

At the moment, the records from Ready, Steady, Go! are currently held in the patient’s notes. Judi is currently investigating whether an electronic version of these can be made available. The intention is that patients will be able to access the records electronically and then can add things, which will notify the clinical team so that they can respond if necessary.

The team are also looking at developing a ‘Hello to Children’s Services’ programme which will be designed for parents and children aged up to 11-years-old, from the moment they get a diagnosis to when Ready, Steady, Go! can take over. ‘Hello to Adult Services’ is also under development. Both of these programmes recognise that transitions take place numerous times throughout a patient’s lifetime and it is important to have a gradual process of change, rather than a step change.

For more information about Ready, Steady, Go! please visit: www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx
A patient’s individual circumstances are not always considered during transition

Most clinical transitions happen during teenage years when there are a lot of other important events taking place in an individual patient’s life, including taking exams and moving schools, or starting college or university. Patients told us that undergoing transition between health services at a different time makes it easier for them to manage. Many of the patients and families we spoke to wanted to see the specific circumstances of their family given more consideration in the planning of transition.

Care doesn’t start and stop with hospital appointments and trips to consultants. Many patients also require support from social care providers. As their healthcare needs change during transition so too will their social care needs. As a result, it is critical that the transition of both social care and health care take place at the same time.

Kayleigh moved from paediatric services to adult services when she was 18-years-old and although her transition from one clinical team to another was smooth, other transitions in her life that were happening at the same time made the clinical transition more stressful than it needed to be.

“It was quite a big time for me anyway because I transitioned literally a few months before I was going to university so I think that was quite stressful as there was quite a lot going on at the same time.” – Kayleigh

80% of rare diseases have a genetic component and because of this, it is not uncommon for more than one family member to be affected by the same condition. This can mean that there might be multiple members of the same family who will need to transition from one healthcare provider to another at some stage. In some cases parents and families felt there can be merit in waiting so members of the same family can transition together.

“When you have a family and two patients are affected and one might be 15 and one might be 18, there’s no flexibility. It would be lovely to think that the oldest one could maybe stay under paediatric services until the younger one is ready to go or vice versa but actually that doesn’t often happen.” – Jane
As the Juvenile Huntington's Disease Care Adviser for the Huntington's Disease Association Helen’s role involves home visits, training for care agencies, local authorities, residential care settings and schools, as well as working with statutory services in health and social care.

“I think with Huntington’s there’s always the wider picture to consider and there could be other family members who are very poorly at the time and there are other caring responsibilities. I know a family where there are three children who have HD and previous experiences impact on how someone experiences the journey and how all of that relates together. I think the hereditary aspect of Huntington’s does add an extra sort of layer, if you like and that will vary from family to family.

There have been quite a few cases I’ve worked with where in theory the patient is an adult, so they may be 18, 19 or 20, but they’re developing early symptoms and I think what often the hereditary aspect means is that they don’t necessarily have the family support around them so if you’ve lost one parent to HD then you’re more likely to be left in a situation where that care might fall on elderly grandparents or there might not really be anyone and that person might be left on their own. Even though theoretically they’re an adult they’re not necessarily picked up in the same way as a child in that situation and if they’ve got early symptoms and they’ve got cognitive difficulties then they can actually end up being quite vulnerable. There have been some very challenging and very sad situations in terms of that and actually for a young adult this lack of support and services in that period can be very difficult if you don’t have a lot of family support around you.”

– Helen

Transition is better for those also affected by more common conditions

Claire’s daughter is also affected by epilepsy and moved over to adult services for neurology without any difficulty, but moving between care providers for her rare condition did not unfold in the same way.

“It was very smooth – we just got an appointment with an adult neurologist and we went to see her and she was very up-to-date with what was happening with Lucy and that went really well.” – Claire

Shelly’s daughter is affected by idiopathic intracranial hypertension and is autistic.

“We didn’t really have any problems with her transition at all, it was totally unexpected. I think her having the autism helped in the sense that they were aware to prepare Katie in advance of any changes happening so we were kept in the loop the whole time.

Yes, that’s what I do think. I mean it’s just my thoughts and we’ve not had anything in writing about the fact that she has autism means her transition will progress a certain way – as I said it was just through discussions at appointments – but I do think that hasn’t have had autism then it might not have happened the way that it did. You know if she hadn’t have had autism and the paediatrician wasn’t aware in advance to prepare her for any changes then she might have had that MRI and gone through surgery under paediatrics and then got halfway through treatment and got to 18 and then have had them said, “goodbye, off you go.” – Shelly