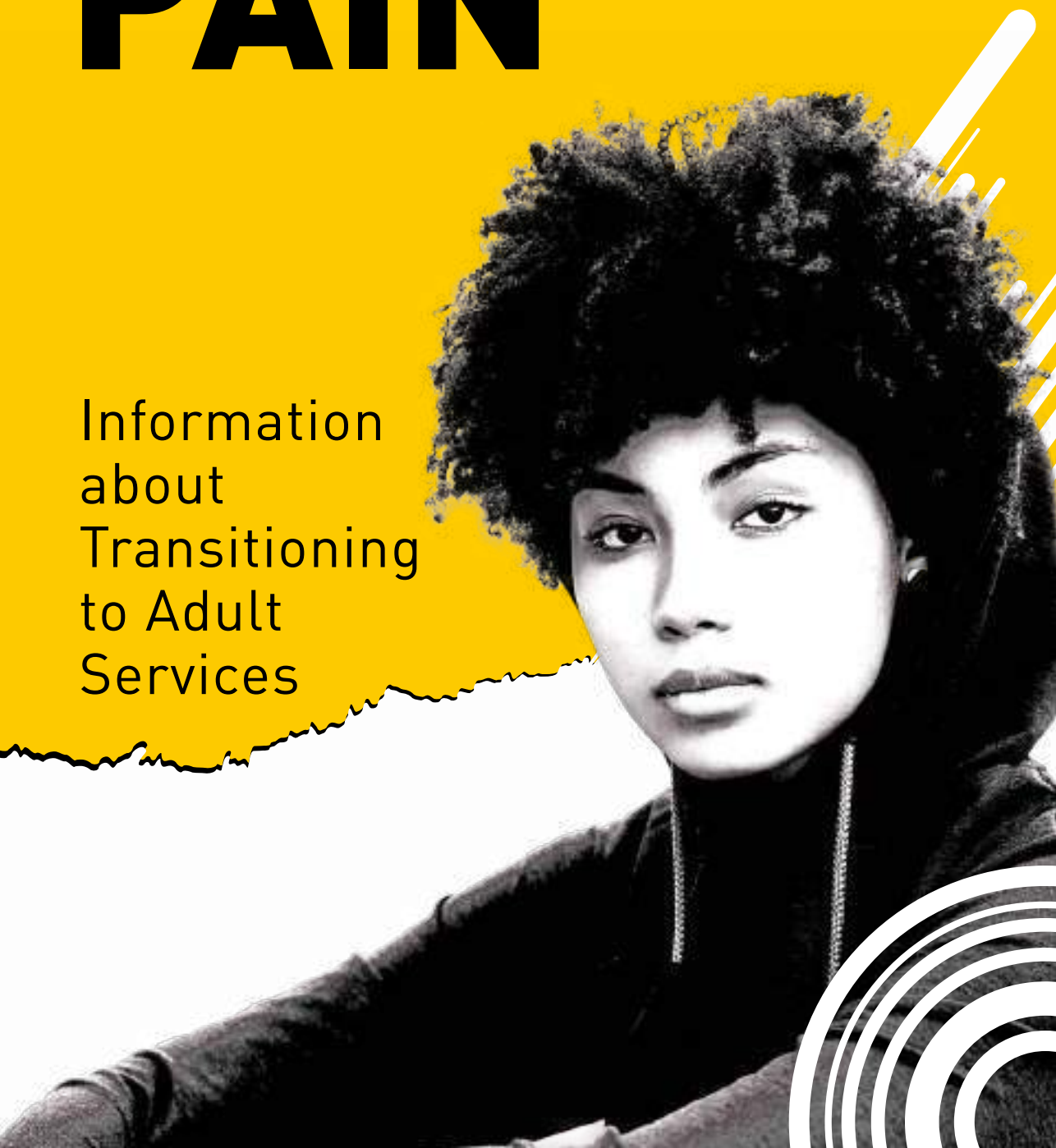


CHRONIC PAIN

Information
about
Transitioning
to Adult
Services



“ I found moving to **adult services a bit scary** because I **didn't really know what to expect.** ”

“ **My mum had always sorted things out but now it was up to me** so it felt **overwhelming.** ”

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The Walton Centre
NHS Foundation Trust



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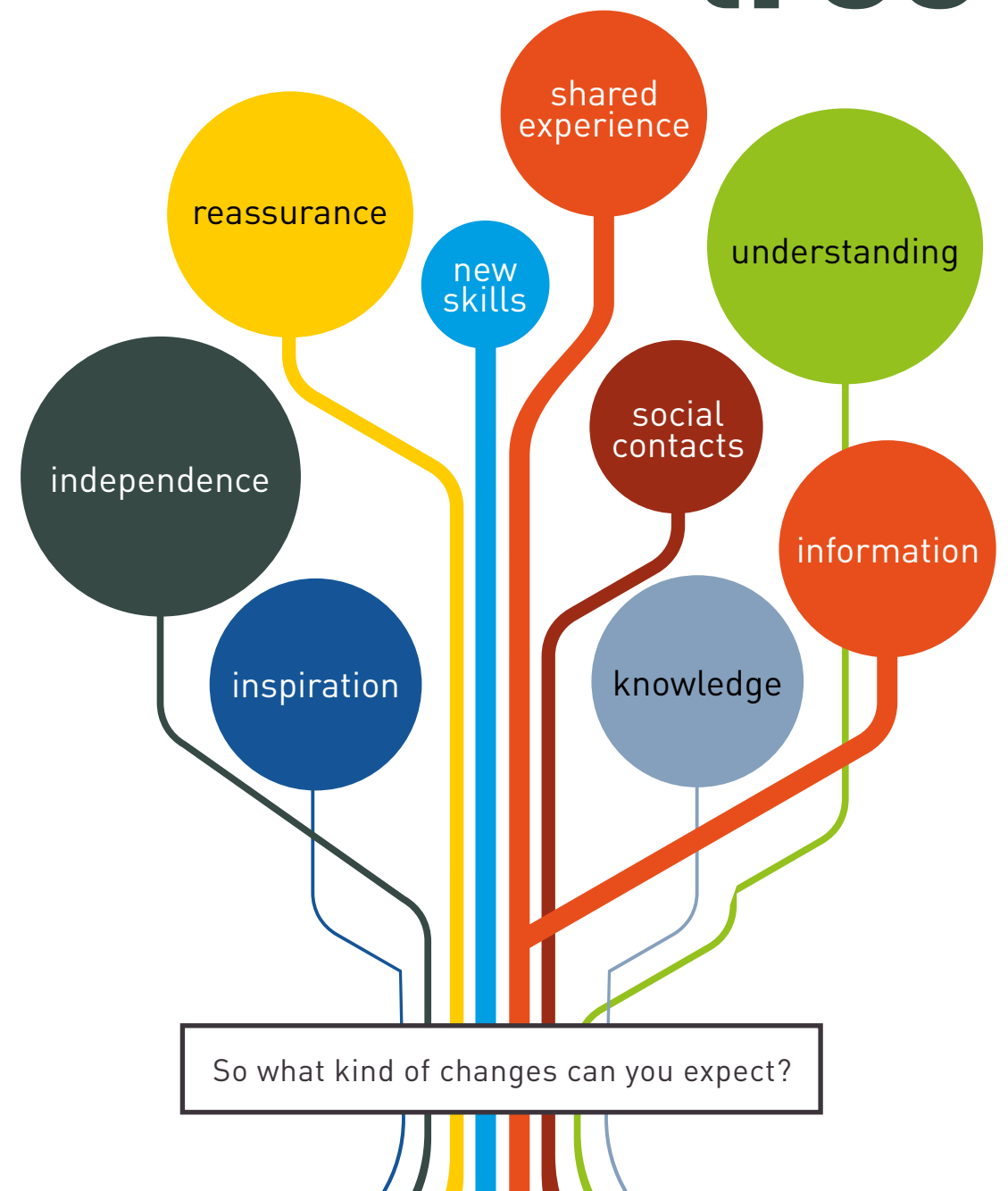
Who is this book for?

This book is for young people and their parents, carers and guardians who are moving, or preparing to move from children's to adult pain management services.

You should be thinking about and preparing for that move from around 14 to 15 years of age.

This booklet helps explain the differences you may encounter, as well as the practical and emotional changes that you may face. It offers some information, advice and tips to help make this transition process as stress free as possible.

The pain management tree



Transition: The basics

What does transition mean to me?

“ Living with chronic pain means I have to visit the children’s hospital for treatment. When I am 18 years old I will move to Adult Pain Services and this will probably mean moving to another hospital and having to get to know new people again. ”

Why do I have to move?

“ When I am 18 and an adult I will become responsible for my healthcare and will need to develop and learn different skills like:

- Making my own appointments
- Getting and being responsible for taking my medicines
- Getting to my appointments and treatments
- Making my own decisions about my healthcare. ”



Transition services

Moving from child to adult services can feel like a big change, due to the different way services are run.

For young people this can be quite daunting, especially as there are some unknowns about adult services.

Transition services aim to help people through this sometimes tricky process, to support you with this change as you start to become more independent and develop new interests as an adult. There may also be new things to consider about managing your chronic pain condition.

“The transition service is there to **support you with these experiences** and **help you plan and prepare** as best as possible.”

“I was a bit nervous about moving from children’s to adult services as I’m used to my mum and dad organising my appointments, driving me there and telling the pain team what’s been going on since my last appointment.”

“I **don’t feel as daunted** as I was because **transition services** have been **preparing me** for what to expect.”

“My pain team at the children’s hospital have been working with my new adult service pain team and me, and together we have been putting together a plan of how we can make the move as smooth and easy as possible. My parents are involved with my transitional teams and the planning process. I want them to be involved at the start and then I’ll think about going it alone as I gain more confidence.”

When talking about living with chronic pain some young people use these words to describe how they have sometimes felt about their experiences and difficulties encountered.

Isolated
Burden
Disbelieved
Embarrassing
Employment **Guilt**
Disconnected
Loss **Age**
Let parents down

Identity
Career Family Plans
Invisible
Socialising
Relationship
Medication
Communication
Uncertainty
Confused





How will transition happen?

Team work

Often during transition from one service to another, your current paediatric team will support you in putting plans together. This will hopefully allow you to feel fully involved and more confident in the process.

The two teams will work closely together to allow this move to be as smooth as possible, helping you to gain independence, whilst supporting you with any issues that may be worrying you.

What about my parents?

You may choose for your parents to be included or not, everyone has different preferences. This may change with time and the teams working with you will support you and your family as much as possible.

When will it happen?

Usually between the ages of 16 and 18 years old, but starting to prepare for this should happen from around 14 years.

The transition from paediatric to adult care should be a gradual, planned process.

The pain team aims to provide support and guidance during this time to make sure you are fully prepared and ready for the move to the adult centre.

They help you do this by planning the process and working together.

Where will my care move to?

Most regions have a local Chronic Pain service. This may be a community-based service or a larger hospital.

At The Walton Centre Chronic Pain service, we have a specialist Pain Transition service with established links with Alder Hey Children's NHS Foundation Trust.

Many aspects of this transition pathway are also available for young adults that are referred to The Walton Centre from other children's or adults' services. The service at Walton consists of a number of health professionals that make up the specialist Chronic Pain management team who will support you moving forward.

“I’ve never been a confident person and I found it really difficult to explain how I was feeling physically and emotionally.”



Carly's story

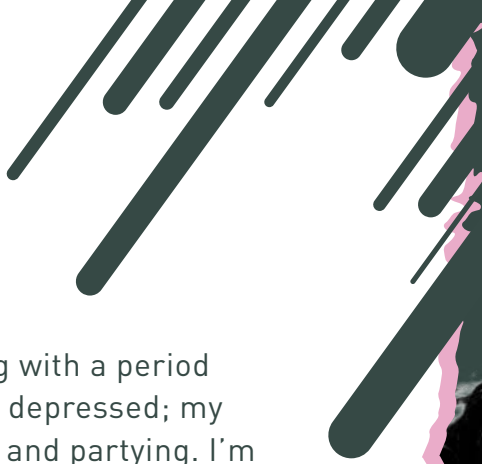
I've had back pain since I was 6 years old. The pain team at the children's hospital helped me understand what the pain meant and how with their and my parents help, I could manage and live with pain better.

It was the doctors and nurses who decided what medication I should take and what therapies I could do; including talking therapies and mindfulness. Once, when the pain got really bad, I had to have an epidural which involved putting medicine in my back via a tube. It was a bit uncomfortable but I was asleep when they did it so it wasn't too bad.

The hospital staff helped me and my mum with all the appointments, supported us and answered our questions.

When I was 16/17 I started college and was discharged from the children's hospital. I started attending appointments at adult services which was in a different hospital. The change in services had been explained to me from when I was about 14, but it was still a big change and I felt quite anxious and scared about it as I didn't know anyone or what to expect.

My mum still wanted to come to my appointments with me but it was explained that it would sometimes be better if I was seen on my own to help me build independence in managing my own care. At first I was anxious and worried as I've never been a confident person and I found it really difficult to explain how I was feeling physically and emotionally.





After twelve months of suffering with a period of really severe pain I felt really depressed; my friends were going out drinking and partying. I'm not supposed to drink due to my medications, but I started to drink too. Then I failed my first year of college, mainly because I didn't attend, but it wasn't my fault, I was in pain all the time and I wasn't sleeping so I was just so tired.

Then all my friends went to University leaving me stuck here, and I felt so low and alone, like life had stopped for me and was passing me by. My mum pointed out that I stopped going to college not long after I had stopped going to my appointments at the pain clinic and as a result I had been discharged from the hospital.

We spent some time talking about my worries and she helped me write a list of things that were important to me and the questions I had about my pain and the future and how I was going to manage.

I realised that my worries had been making me feel low with no motivation to get stuff done or look after myself. So I started to build my confidence by taking some responsibility for my own health, taking small steps like getting back in touch with friends and going out a bit more as well as getting in touch with the pain clinic and making appointments, which I attended and they helped me get some support.



“ I've got more hopes for the future and I feel better knowing I can use healthcare **when I need to** and **by building on my independence I might reach my goal of going to university next year.** ”

Young me

What is going to happen?

I'm finding it all scary because I don't know what is going to happen. It's a new hospital, I've never been there and I don't know the doctors, they know all about me but I don't know them. It's stressful.

I don't know what to ask?

I don't really know much about the management of my condition or what I need to do now because my parents have dealt with it all.

Can my parent/guardian still come with me?

I want to take my mum in with me, she knows all this stuff, it's easy for her because she has done it for so long. To be honest, I feel a bit overwhelmed by it all. Won't it be easier if she does it now as well?

I have never dealt with this stuff

I don't know where to start with my medication or how to order it, or how to make an appointment. I am scared because if I am expected to do it, how do I know how to?

Older me

Try not to be scared

All the instructions will be on your appointment letter. When you go to your first appointment in adult services, you will be guided through this by staff and your confidence will build over time.

Be responsible for managing your condition

Sometimes you have to read about your condition or ask the pain team for information about it. Educate yourself so you know about it and feel empowered to look after yourself. Take a list of questions to your appointment and don't be afraid to ask the questions and/or write things down to help you remember. It can also sometimes be helpful to keep your important documents/letters in a folder as you go along, so that you have this information to hand and in one place for when/if you need it.

Be more independent

When you are an adult you are expected to be responsible for yourself. It's not as scary as it seems, it makes you feel confident. When you make decisions about your life and your condition, you feel more in control and less scared of what is going to happen.

Try not to rely on your parent/guardian to do everything for you

As an adult, the pain team can't just talk to your mum, because you are the adult. My mum did everything for me, but actually I realised that I needed to start doing it for myself. I wish I'd been involved with getting my medication, learning about my condition, speaking to the medical team and making my appointments much earlier. I think it would have made it easier for me in the long run.



Differences & similarities

It is understandable that you may feel a bit nervous about what to expect when you move into adult services. Here are some differences that are worth knowing about.

In Children's Services...

Focus & Independence

Doctors and health professionals often speak to your family first.

In children's services, your family will have been involved in a lot of your care.

Knowledge & Responsibility

Your parents/guardians would have answered a lot of questions and made most of the decisions around your care and treatment.

Communication Styles & Appointment Length

Your parents/guardians may have had more communication with your doctors than you.

Doctors may have spent longer in appointments explaining things to you.

Waiting Times

You may not have had to wait for very long for appointments or you may have had regular/ongoing contacts with the same people in the team

In Adult Services...

Focus & Independence

You are viewed as more independent and so will be invited to take part in more discussions about your care.

This is a gradual change as you feel more confident and comfortable with these conversation and decisions.

Knowledge & Responsibility

You have more responsibility over your care and important decisions about your condition.

It is helpful to learn about your pain condition. The pain team will be able to answer questions you might have and support you in your understanding of your pain.

You may ask your family for advice on what questions to ask or what to say when at your appointment. You can also ask them to come with you to the hospital itself.

You will have the responsibility to book/chase/respond to appointments or hospital letters.

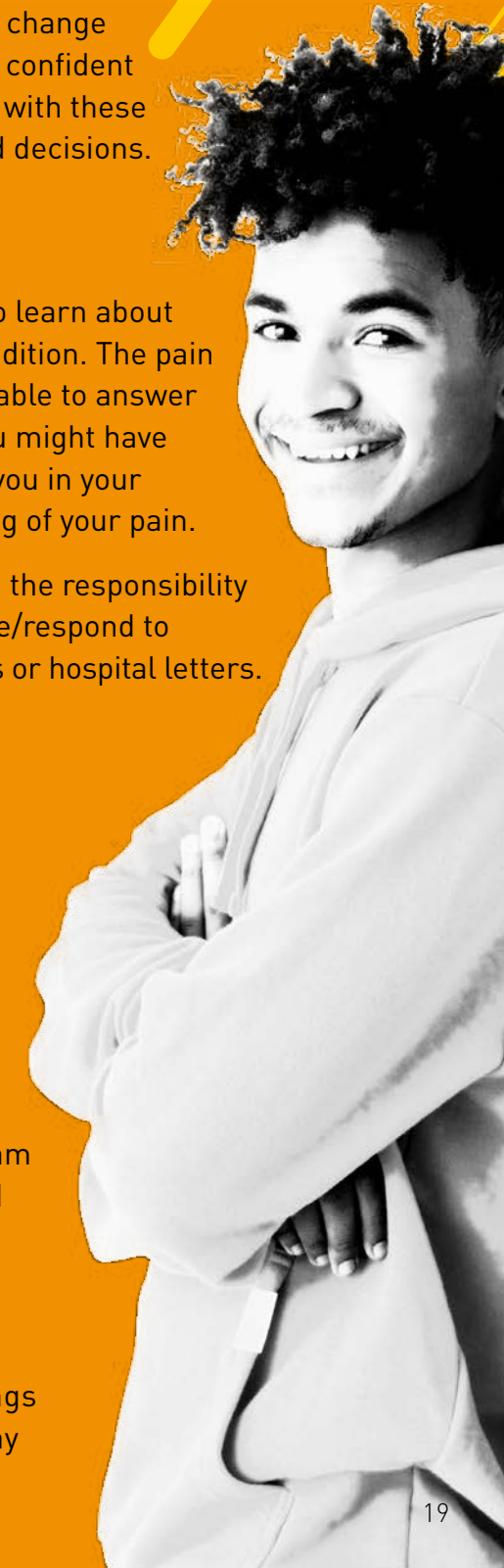
Communication Styles & Appointment Length

Doctors may spend less time with you in appointments and these may be a bit shorter in length than what you have been used to.

Communication styles in child services can be very different to adult services. This can feel scary and confusing, especially if you have less time or are seeing new/different people. The team in adult services will answer your questions and make the change as smooth as possible.

Waiting Times

Waiting times to see people and actioning things often take longer in adult services and you may not see the same person each time.



“It is **normal**
for this to **feel**
daunting!”

How are they similar?

Both put your care and your health at the forefront of what they do

They will have a similar understanding of what might be helpful and will be just as open to answer any questions or concerns you might have.

Your local Adult Pain Services will be located at The Walton Centre in Liverpool

You will most likely see an allocated Pain Consultant, who is a medical doctor in charge of your care. You will most likely also see other members of the Chronic Pain specialist team such as Pain nurses, Physiotherapists, Occupational Therapists and Clinical Psychologists.

This team may be similar to the team you had in child services.

The team will liaise and communicate with one another regularly so you receive the best care possible.

Medical teams also work with other health professionals to provide the best quality of healthcare to help you manage your pain condition.

Introduction to the Pain Management Team

The Pain Teams are interdisciplinary teams, made up of a group of professionals who work together so you receive the best care. When you attend pain clinics you may meet a number of different people who all specialise in the management of Chronic Pain.

“**Consultants** in Pain Medicine are **doctors** who **specialise** and **work** in **Chronic Pain Services**.”

Consultants in Pain medicine



They can talk to you about how Chronic Pain can develop and continue and how this may impact on your life now and in the future.

They can help explain your body and pain symptoms better, so that you have a good understanding of your condition and the difficulties you are experiencing.

They may also talk to you about how certain medications work, and the most effective way to use medication alongside other pain management techniques and treatments.

Occupational Therapists support people with **chronic pain** to **manage** their **daily activities**.

They help people identify how pain is impacting on their activities and enable people to return to activities that are important to them. This is achieved through setting and working towards realistic targets and breaking them down into small achievable chunks.

People in pain often find themselves caught in a pattern of good and bad days. They will try and fit everything into a good day and find that they are then struggling with increased pain.



Occupational Therapists also teach mindfulness skills. Mindfulness is about being aware of what you are doing, your surroundings and creating choices around what you pay attention to.

This is useful in pain management as pain (and thoughts about pain) are very attention grabbing. It can also help us to be more aware of our emotions and make more informed, fewer pain led decisions as a result of this improved awareness.

“ Occupational Therapists teach **pacing** and **activity management strategies** and steadily building up **activity levels**, allowing more **consistency for people** to be able to be **active each day**. ”

Occupational Therapists

Physiotherapists help people **improve** what they are **able to physically** do on a **daily basis** so they can **achieve** more **enjoyable** and **consistent activity levels** despite pain.

- Physiotherapy you have had in the past may have involved treatment techniques being done to you. In adult pain services treatment is centred around giving you exercises and information that you can use yourself, to independently manage your pain and physical function in the long term.
- Chronic pain often affects the way we hold ourselves and the way we move. This can lead to us avoiding or reducing certain activities that are painful to do. The physical impact of this often means we lose physical stamina and flexibility.

■ Physiotherapy sessions use gentle low intensity exercise to gradually improve flexibility and stamina. This reduces some of the physical impact that comes with long-term pain.

■ The most important thing about exercise is that it is sustainable and adapted so you can comfortably and confidently repeat them on a daily basis.

“**Physiotherapists will work with you to enable you to return to, or start exercising in a way you feel safe to continue by yourself.**”



Physiotherapists

Clinical Psychologists who work in **Chronic Pain Services** can **help people** to **think** about how their Chronic Pain can **impact** on their **mood**, their **thinking** and **how they cope** day to day.

- They can help someone to consider how pain might also impact on other areas of their life such as relationships and education/career.
- They may provide an opportunity to help people make sense of the difficulties they may be experiencing with having a long term pain condition, and to help with managing distress and the impact on someone's wellbeing and lifestyle.
- Learn practical techniques and coping strategies, which can at times be provided on an individual and group basis depending on what someone feels comfortable with.



Clinical Psychologists

Some suggested questions for you to think about before you transfer to Adult Services.

What might I need to know or do before I move services? ■

What might it be like to be a young adult living with Chronic Pain? ■

Could Chronic Pain impact on my education or career? ■

How might my family be able to prepare me for transition? ■

When can I begin getting more involved in my health care and treatment? ■



What about support around my future education and employment?

Embarking on a new career or maintaining employment and education can sometimes be challenging when living with chronic pain. Here are some resources that you may find useful.

The National Careers Service

The National Careers Service gives free and impartial information and advice to help you with making decisions about your future career, courses you can do and work options. The service is available to people who live in England and is supported by qualified careers advisers.

www.nationalcareers.service.gov.uk/contact-us
Tel: 0800 100 900 or text 07766 413 219

Job Centre Plus

If you have a health condition or a disability that affects your ability to work, you can get assistance and advice on returning to the workplace by speaking to a Work Coach at your local Job Centre Plus.

www.gov.uk/contact-jobcentre-plus

UCAS

Universities and colleges have well developed systems, grants and procedures for supporting disabled students and making sure they progress in their studies and have access to the additional support they need whilst studying.

www.ucas.com/support-disabled-students-your-questions-answered

Career Connect

Career Connect is a charity that provides independent careers advice, particularly around bridging the gap between learning and employment for young people and adults. They provide a wide range of career management services, some funded by Local Authorities and schools and colleges.

www.careerconnect.org.uk/ Tel: 0800 012 6606

The Prince's Trust

The Prince's Trust offers a variety of programmes and funding opportunities for young people aged 11-30 to support them to access education and employment.

www.princes-trust.org.uk/ Tel: 0800 842 842

Even Break

Even Break is an organisation that supports people with disabilities into work by posting adverts by companies who are proactive in employing people who are struggling with disabilities and keen to look beyond disability to identify what skills the person has to offer.

www.evenbreak.co.uk/en

Remploy

Remploy is a leading provider of specialist employment and skills support for people with a range of disabilities and health conditions.

www.rempoy.co.uk/

AbilityNet

AbilityNet supports people of any age, living with any disability or impairment to use technology to achieve their goals at home, at work and in education. They do this by providing specialist advice services and free information resources.

www.abilitynet.org.uk/

Agency Central

Is a fast and easy way to find a career specific recruitment agency in your area.

www.agencycentral.co.uk/

Turn2Us

Turn 2 Us has a free and easy-to-use benefits calculator and grants search tools to check what benefits you might be able to claim and what grants you might be able to apply for.

www.turn2us.org.uk/ Tel: 0808 802 2000

For Parents: What does transition mean for my child and me?

What is my role as a parent?

Usually, between the ages of 14 to 18 years old, alongside children's services, you will be involved in helping to prepare your child for the transition from children's to adult pain management services.

The pain team can help you with this transition and it is worth you asking them for any available information they have and asking questions to help prepare for the transition process for you and your child.

Why does this move need to happen?

As Chronic Pain may continue into adulthood, it can require the input of a specialist adult interdisciplinary Chronic Pain team.

As children mature, it is a time for them to make their own decisions around their care and treatment. There is more of a need to manage their health alongside other important aspects of their life such as education and relationships, together with building an understanding of how their condition might impact on their life moving forward.

As people go through this transition from being a child into young adulthood, they may experience various difficulties and emotions and may need continued support in new and difficult situations, which the adult team will be experienced in providing.

What differences in services might you notice?

You may notice that whilst child teams work closely with children and parents, adult teams are likely to work more closely with your child.

Whilst your role might change slightly, you may still want to have input into your child's care by providing advice around decisions and treatment, alongside asking the team any questions that you may have, or suggesting these questions to your child to ask.

The adult team will provide support, both practically and emotionally, to your child so that they are able to become more confident managing these situations independently.

What will my role be?

In child services you will have likely supported your child throughout their care and treatment and may have taken a lead role in making decisions around their health care.

It is important to now allow them to begin making their own informed decisions as they mature. As this can be a new and sometimes worrying experience for a parent, the team will support you with any questions or concerns you might have along the way. It can be difficult to achieve this change if your child initially struggles to adopt these new adult responsibilities, however continued reassurance and encouragement is useful in this situation to improve their confidence as their skills develop over time.

Your child may still seek practical or emotional advice from you, which is just as important as the previous support you may have given. It is also natural for developing young adults to begin to seek support and advice from other people in their life as they mature, such as friends or colleagues.

When will the move be?

Different services work in different ways but the majority of children's services discharge at 18 years' old. As children mature gradually, the child and adult teams may begin involving you and your child in the process of transition planning early on, from the age of 14/15 years and onwards and informing you of what to expect.

Our team at The Walton Centre regularly hold transition clinics, where both the child and adult teams are present, at which point you will be able to ask any questions or raise any concerns that you have.

Helping your child to take **personal responsibility** is **key** to your child's **successful transition into adult services.**

Previously you may have helped with things like:

- Booking appointments
- Attending appointments
- Travel to and from appointments
- Updating staff on your child's condition
- Telling staff about medical symptoms
- Describing your child's behaviour and difficulties
- Ordering, collecting and administering medication

You can start helping your child by explaining what taking responsibility means and what this might look like when they move into and start navigating adult services.

You can support them to become confident and independent young adults by guiding them to manage their own condition and treatment.

Appointments

Some tips to encourage confidence in your child to attend appointments on their own include:

1. Easing them into the process by going with them to the first or second appointment/s.
2. If you are attending an appointment try to go as an observer; let them speak for themselves; try not to interrupt; even if they are reluctant to speak for themselves. This can be really difficult to observe as a parent but it is crucial to helping them build their confidence in adult services and developing their own voice.
3. It might be appropriate to go in with them and leave after 10 minutes, either waiting for them outside in the waiting room or in the car. This may help settle them into the appointment and reduce any initial anxiety whilst supporting them to take ownership of the appointment and their medical care. Discuss this with the clinician in advance so that they can help structure the appointment and support the plans you have made together.
4. Talk to your child about things they might want to discuss at their appointment prior to the meeting so they feel more prepared.
5. Support your child to make a list of discussion points to prompt them whilst talking to the doctor/team. This is a common technique used by patients and the doctor will be familiar with it, and it can also help to reassure your child that this will be supported by the team.
6. It might seem an insignificant point but is actually very important to encourage your child to arrange and cancel their own appointments. Try not to be tempted to do it for them, even though this may speed things up. Setting these boundaries and encouraging autonomy helps your child to be confident in health care settings in the future so that they know how to get their needs met.

“The pain team at the hospital were amazing. Not only did they support and reassure Karl but they have helped me too.”



A parent's story

When Karl was diagnosed with Juvenile idiopathic arthritis I was devastated. He was only 6 years old when we were told he suffered with chronic pain.

At first I was overwhelmed and felt incapable of caring for a young boy with chronic pain properly, I didn't want to see him in pain. I thought it would effect his future by stopping him from getting the education, social life and job he deserved.

The pain team at the hospital were amazing. Not only did they support and reassure Karl but they have helped me too. I have found the team's advice to be vital, from when Karl was first diagnosed, right up to planning his transition to adult services.

They have supported me to acknowledge and understand Karl's pain whilst encouraging him to be resilient and independent which has made his transition to adult services much easier than I thought. The team have been planning and preparing Karl and myself for his move to adult services from the age of 15 years, so we knew what to expect, Karl is very confident and independent.

Karl doesn't manage everything perfectly but he manages his own appointments, medication and is confident when speaking to members of the pain team. We have been lucky to have had the team's expertise to guide us through the transition process.

Quotes from parents of young people transitioning to adult services:

“It is difficult, because you never think anybody could look after your child the way you’ve looked after them. But you have to let ‘em. You have to let them try and do things for themselves. And, I don’t, wrap her up in cotton wool to be fair, I do check her a bit more, ring her a bit more but I let her do things*”

“You want to know what to expect, what will be so different compared to what you were used to**”

“Therefore the fact that we knew people here – simply because we’d met them already and that was a really helpful start to our life in the adult world*”

“When you’ve been through an event like that with the certain staff you do get a bond because they’ve seen you at your very worst when you’ve been running round corridors crying your eyes out and things so you get a sort of bond with people which you would lose*”

“As a Mum it’s absolutely terrifying to have to let go and to trust that she understands her conditions so well that I don’t have to worry...**”

“It’s completely different because they weren’t talking to me, in the adults, they’re talking to her. And because I’m used to it, I know I do speak for her sometimes, but you just do, it was as if ‘you be quiet, she needs to talk, she’s an adult now’. I thought, but hang on, she’s not*”

Quotes taken from research: *Wright, Elwell, Donagh, Kelly & Wray, 2016, “Parents in transition: Experiences of parents of young people with a liver transplant transferring to adult services”, *Pediatr Transplantation*, 21, 4-6

**Aldiss, Ellis, Cass, Pettigrew, Rose & Gibson (2015). “Transition from child to adult care – ‘It’s not a one-off event’: Development of benchmarks to improve the experience”, *Journal of Paediatric Nursing*, 30, 5, 638-647.

Things to consider during transition

As you plan for your child's transition, it can be helpful to consider the different experiences and skills you may need to be aware of and develop to better prepare you. Below are some questions you and your child may want to ask yourself or the professionals involved in your transition.



The Walton Centre

Here is an example of what a pain management department looks like and where you may go for your appointments.

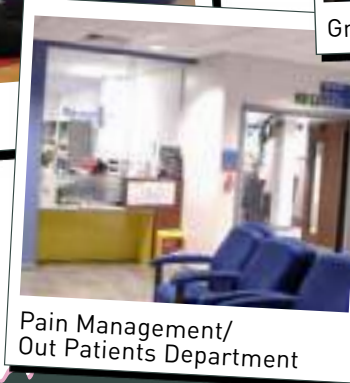
- Do I understand the need for transition?
- Have I had a chance to ask the adult/children's team my questions?
- Have I spoken to someone about what transition is and how/why it's different?
- Have I met the adult team?
- Have I visited the adult centre?
- Is there a plan in place and have I been involved in this process?
- What is the difference between child and adult services?
- Can I/Do I have to go in to my first couple of appointments on my own?
- Is there someone I can contact if I needed too?



The gym




Group rooms



Pain Management/
Out Patients Department



Common room



Pain Management Programme,
Sid Watkins Building, The Walton Centre,
Fazakerley, Liverpool. L9 7BB

0151 556 3161

Website:

www.thewaltoncentre.nhs.uk/112/pain-management-programme-pmp.html

Read our Blog:

www.painmanagementprogramme.wordpress.com



@waltoncentre



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