



# Moving from child to adult care services

A guide for carers

# Introduction

This guide provides some introductory information to help you understand the process involved when your child moves from child to adult services for their ongoing care needs.

It may be difficult to find out what should happen when and what your rights are, or how involved you should be as their carer or parent. We aim to help provide an overview with some useful tips.

## Terms you might hear

The move from child to adult services is often referred to as a **transition** by health and social care professionals. We explain the part you can play to support your child and what to expect. Planning and preparing at an early stage will help make the process easier.

In Scotland, NHS Continuing Healthcare is called **Hospital Based Complex Care**. It is only available in a hospital setting. You can find out more about the Transition Care Plan in Scotland on the [NHS Inform website](#).

It may also be helpful to note that transition in the healthcare system is often referred to as **NHS Continuing Healthcare**. This is different from the social care system, which is run by social services.





# Contents

What should happen?	4
What rules apply where I live?	6
In England	6
In Wales	7
In Scotland	8
In Northern Ireland	9
Useful questions to ask or consider as a carer	10
How can I find out more about the support my child could receive as an adult?	10
What happens with financial benefits?	11
How do I challenge a decision if I'm not satisfied?	12
Further resources	14

## Join Carers UK for support, understanding and lasting change

However caring affects, you, we are here for you.

By joining Carers UK, you can be part of a supportive community and movement for change. It's free to join us.

Visit [carersuk.org/join](https://carersuk.org/join)  
or call **020 7378 4997**



# What should happen?

It may be helpful to know that there is no single point of transition. The change from childhood to adulthood services should be a gradual one.



4

Ideally, the transition should begin during your child's early teenage years. They should be supported by a named worker who should consider what support they will need as part of a review including:

- ✓ **your child's health**
- ✓ **their emotional and communication needs**
- ✓ **their mental capacity** (ability to make their own decisions)
- ✓ **any peer support, coaching or mentoring they need**
- ✓ **their ideas and plans for the future**
- ✓ **any advocacy needs.**

Your child should be as fully involved as possible about any decisions related to their future aspirations and needs. You should also be able to have a say and play a central role in decision making as their carer or parent.

As a carer, you should be supported through these changes. You can find out more about your rights in:

- ✓ **The Care Act 2014 and the Children and Families Act 2014 (in England)**
- ✓ **Social Services and Well-being Act 2014 (in Wales)**
- ✓ **The Carers (Scotland) Act 2016 (in Scotland)**
- ✓ **The Carers and Direct Payments Act 2002 (Northern Ireland).**

Your local authority (or local Health and Social Care Trust in Northern Ireland) has a duty to help prevent your own needs from escalating so that you can continue your caring responsibilities if you want to.



## As your child approaches the age of adulthood

Legally speaking, a child becomes an adult at age 16 in Scotland and 18 in England, Northern Ireland and Wales.

We know that many young people are likely to continue to need support to make decisions after reaching adulthood. The time when your child enters adult health and social care services will vary depending on where you live and your circumstances, or the way the services operate in your area. For example, some children may access some adult health services before they have turned 18.

- ✓ **It is a good idea to check with each service provider when the transfer will take place and who the key contact will be to introduce the new service.**

## The care package

A care package should be put in place for your child to ensure that all their physical, social and emotional care needs will be met. As their needs will inevitably change over time, it's important to work closely with any social services and healthcare professionals involved.



# What rules apply where I live?

The processes for the transition of care for your child are likely to vary depending on where you live in the UK.

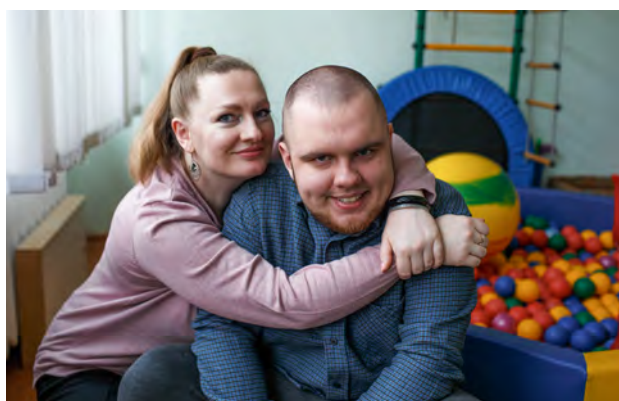
## In England

There should be no gaps in services for the child or young person during their transition from child to adult social care services. These services should also be tailored to their needs as a young adult.

When they have turned 18, the local authority will decide whether it's necessary to provide a needs assessment under the Care Act 2014 as part of their transition in care. Contact your [local authority](#) to find out more details.

There are no set timescales for the transition assessment to be carried out, but it must be during a reasonable period and before the young person reaches the age of 18. You should be kept informed by the local authority about when the assessment will take place and the overall timeframe.

An Education, Health and Care Plan (EHCP or EHC Plan) is available for children and young people with significant additional support needs up to the age of 25. An EHCP is a legal document that sets out the young person's educational needs and goals. This plan should be reviewed if already in place. If the young person is aged from 16 to 25, they can request their own plan.



However, a parent, doctor, teacher or family friend can also request one from the local authority on behalf of the young person.

The plan aims to provide guidance on:

- ✓ **learning and future employment**
- ✓ **home and independence**
- ✓ **friends, relationships and community**
- ✓ **health and wellbeing.**

It is a legally-binding document and should focus on the child and parents' preferences and needs. The charity Contact has some helpful explanations on their [online pages](#). You can also contact your local authority to find out more about EHCPs and other local support services.

Further formal support can be requested as part of an assessment through your local authority. You can search for your [local authority's contact details](#) on the gov.uk website.

On the NDTi website, there are many helpful resources under [Preparing for Adulthood](#). For more information about your legal rights, you could refer to the [Children and Families Act](#) (Part 3) and [The Care Act](#).





## In Wales

Every local authority has a duty of care to provide young people up to the age of 25 with special needs support if required.

Your child and you as their carer should remain at the heart of decision-making, with your child's care, support and wellbeing needs considered throughout the process. The relevant health and social care teams should also work together and share information in a timely manner.

In schools, children who need extra help with learning should have additional support in

the form of a development plan. You can work with the school to help develop an appropriate plan for your child to help them reach their potential. You can read more about this on [Contact's website](#).

When a child is about to turn 16, the local authority should prepare a pathway plan to help that young person with the transition to adulthood. The pathway plan is designed to build upon the child's existing care and support plan.

## In England and Wales

Applications for support in the form of adult Continuing Healthcare support or adult social care funding can be made from the age of 17, although the process of transition can begin from 16 or earlier. It is important to be aware that the transfer of support will not happen until the individual turns 18. The child will need to be assessed by health and social care professionals to see if they are eligible for this support.

Find out more on the [NHS website](#) and [GOV.WALES website](#).

## In Scotland

From 12-15 (before a child turns 16), they have the right to:

- ✓ **have an advocate with them at meetings and appointments about their support needs** (an advocate is someone who can speak up on the child's behalf and help them express their views and preferences)
- ✓ **challenge decisions formally**
- ✓ **request a coordinated support plan (CSP) from their local authority or find out if they need one**
- ✓ **contact their local authority requesting help to assess their needs.**

Legally, a child becomes an adult at 16 in Scotland. The rules for the transfer of care from child to adult services are outlined in the [Additional Support for Learning \(ASL\) Act](#).

After your child turns 16, they will be seen as a young person rather than as a child. This does not mean they are expected to make decisions alone or at all if they are not able to.

You can be closely involved in helping your child to receive ongoing care and support as their parent/carer. They may be able to request an adult support plan assessment of their needs from their [local authority](#) or you can request this on their behalf. At least 12 months before the child leaves school, their local authority and school should also work together to help them prepare for adult life.

They may already have a Coordinated Support Plan in place. You can find out more about these by reading [Enquire's factsheet on Coordinated Support Plans](#).

For more details about your legal rights, see the [Additional Support for Learning \(ASL\) Act](#) and the [Adults with Incapacity \(Scotland\) Act 2000](#).

The **Adults with Incapacity Act (Scotland)** is the law that can provide an appointed person the ability to make decisions on another's behalf if they are unable to.





## In Northern Ireland

In Northern Ireland, the process of moving from child to adult services usually takes place around the ages of 16 to 18. What services will offer will vary depending on where you live.

Young people in their teenage years (who have the ability to make decisions) should be introduced by professionals to a transition plan. This should allow them to focus on their future goals and aspirations. The plan covers important matters such as having an assessment for any ongoing health and social care needs. You can find out more about this on the [Education Authority for Northern Ireland website](#).

Health and social care professionals should liaise with you as the parent or carer as well as the child, if appropriate, to make sure a thorough review of their needs takes place.

You can find detailed guidance about what to expect on the [nidirect website](#).

There is legislation confirming that every child with palliative care needs should have an agreed transition plan involving health and social care professionals to ensure that their needs are met. This plan should be agreed at least six months before the transition is due to take place. It is detailed under [The Integrated Care Pathway for Children and Young People with Complex Physical Healthcare Needs](#) (DHSSPS 2009).

There is further useful guidance about this available on the [nidirect.gov.uk](#) website.



# Useful questions to ask or consider as a carer

You should be supported and kept informed about the process of moving from child to adult care services.

## Here is a helpful checklist of questions you may wish to consider:

- ✓ Have they told me what will happen before, during and after the transition process?
- ✓ What support will be available? How will I manage their care and support needs as an adult?
- ✓ Have they informed me what advocacy, information and advice services are available?
- ✓ Am I aware of all the benefits and financial support we could be entitled to? Have we been given information about organisations or services that can help us apply?

10

## How can I find out more about the support my child could receive as an adult?

There are ways in which you (and your child) can become more familiar with any support services they may be able to use as an adult. You could ask if it's possible to arrange a visit to see how they might work in practice for example at a day centre.

You could also feel more prepared by reaching out to other parents and carers in a similar situation via forums such as [Carers Connect](#) or through local carer and parent support groups. Requesting joint appointments is another way to help make sure that you are kept fully informed.

The charity [Contact](#) provides specialist guidance for families with disabled children.

In Northern Ireland, a carer coordinator at your local [Health and Social Care Trust](#) should be able to point you in the right direction.







## What happens with financial benefits?

It's important to remember that any benefits your child has been eligible for as a child are likely to change as they become an adult. This may impact your household income, and could reduce it if they are no longer considered a dependant.

You may also need to make arrangements to manage their affairs on their behalf. One way of doing this is by becoming an appointee. You can read more about what options are available on our [Carers UK website](#).

It may be the case that you or your child become eligible for extra money or support that you hadn't considered before. In any case, it may be helpful to arrange a benefits review before your child makes the move to adult services.

For example, your child may have been receiving the disability benefit Disability Living Allowance but now needs to move over to Personal Independence Payment.

In Scotland, if your child is receiving Child Disability Benefit, they will continue receiving this until they reach 18 and then will move over to Adult Disability Payment.

If you're already receiving financial support, certain benefit offices should also be in contact with you to notify you of any changes, such as transferring to a different benefit. You can find out more details about this on the [NHS website](#) or [Social Security Scotland website](#) in Scotland.

You can also request a benefits review by emailing one of our benefits advisers via our Carers UK Helpline: [advice@carersuk.org](mailto:advice@carersuk.org). If you're based in Northern Ireland, we would recommend contacting the organisation called [Make the Call](#) who can carry out a full benefits check.

## How do I challenge a decision if I'm not satisfied?

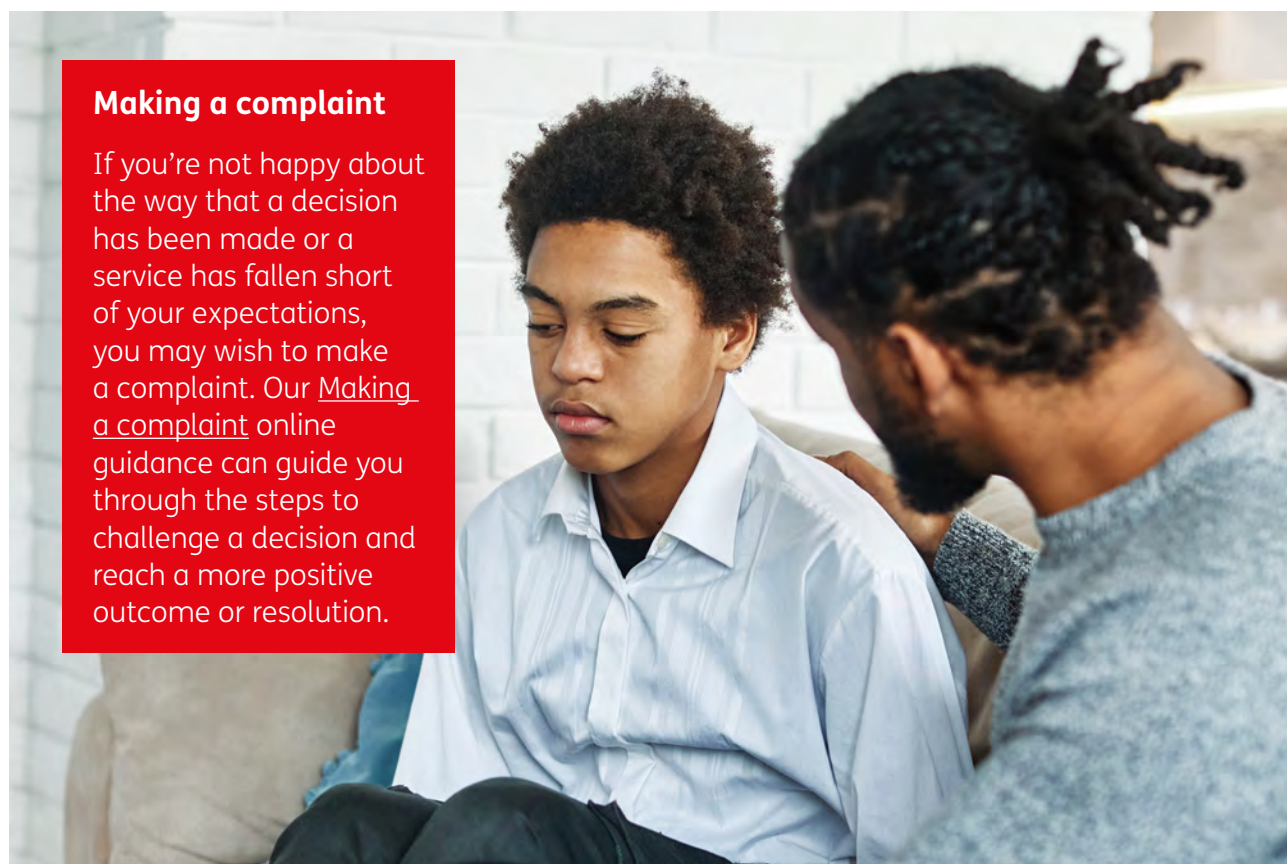
Sometimes we feel let down by key decision makers, processes or service providers. Seeking a second opinion is often helpful if you're not sure about a decision or a service that's being offered.

For example, it may be helpful to take written notes of any phone calls or meetings, making a note of the time and date, who you spoke to and what you discussed.

- ✓ **Always try to keep a record of your communications in case you might need to prove anything about your child's needs for support in the future.**

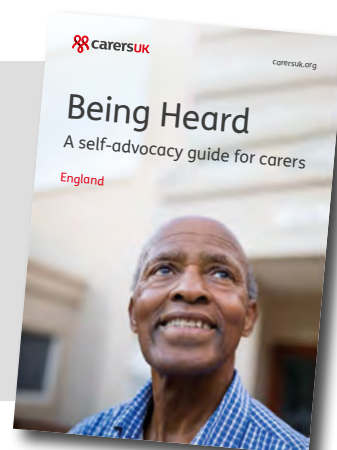
### Making a complaint

If you're not happy about the way that a decision has been made or a service has fallen short of your expectations, you may wish to make a complaint. Our [Making a complaint](#) online guidance can guide you through the steps to challenge a decision and reach a more positive outcome or resolution.



### More guidance

Our [Being Heard](#) guide offers more guidance and support to help you understand your rights and communicate your needs as a carer. There are individual guides for each nation explaining the different legislation and processes involved. On our website, you can also find a [template letter](#) as a helpful starting point for making a complaint and a [guide for challenging benefits decisions](#).









# Further resources

We know that this can be a confusing and difficult time, especially when different rules may apply in different areas and some services may not always appear to be joined up.

We've put together a list of organisations that can offer further support if needed below:

## Carers UK

Find out more about [needs assessments](#) for your child on our website and by referencing our nation specific factsheets. We also provide lots of guidance about [your rights as a carer](#).  
[carersuk.org](http://carersuk.org)

**Citizens Advice** is a national charity offering information on your benefit rights. You can call the relevant number for your nation:

**T:** 0800 144 8848 (England)

**T:** 028 9026 2532 (Northern Ireland)

**T:** 0800 028 1456 (Scotland)

**T:** 0800 702 20 20 (Wales)

Their website also provides lots of helpful guidance tailored to where you live:  
[citizensadvice.org.uk](http://citizensadvice.org.uk)

**Contact** can offer support, advice and information for families with disabled children:  
[contact.org.uk/](http://contact.org.uk/)

**Disability Rights UK** is a charity that campaigns for better rights for disabled people across the UK. They offer a helpline for disabled students:  
[disabilityrightsuk.org/disabled-students-helpline](http://disabilityrightsuk.org/disabled-students-helpline)

The **Gov.uk** website [Gov.uk](http://Gov.uk) provides an overview of the support available and guidance on options around transition in health and social care.

The **NHS** website [NHS.uk](http://NHS.uk) provides a useful overview of the process of moving from child to adult social care services and a summary of what to expect.

**NHS inform** provides helpful national health information and guidance on transition in Scotland: [nhsinform.scot](http://nhsinform.scot)

**NI Direct** is the official government website for Northern Ireland and offers helpful information and guidance: [nidirect.gov.uk](http://nidirect.gov.uk)

**Relate** can offer counselling services for young people aged 11-18 as well as family counselling. See the website directory to contact your local branch: [relate.org.uk](http://relate.org.uk)

**Relationships Scotland** provides relationship counselling, family mediation and child contact centre services:  
[relationships-scotland.org.uk](http://relationships-scotland.org.uk)

The **Scottish Government** has a guide for parents with sections on transitions in health and social care:  
[gov.scot/publications/supporting-disabled-children-young-people-and-their-families/pages/adult-health-and-social-care/](http://gov.scot/publications/supporting-disabled-children-young-people-and-their-families/pages/adult-health-and-social-care/)

**Sense** is a charity that supports and campaigns for the deafblind living in England, Wales and Northern Ireland. Their services include one-to-one support to help people live independently, as well as guides on communicating, housing, holidays and employment opportunities.

**T:** 0300 330 9256 | [sense.org.uk](http://sense.org.uk)

## Sense Scotland

**T:** 0300 373 0808 | [sensescotland.org.uk](http://sensescotland.org.uk)



# *Being Heard: a guide to self-advocacy for carers*

This guide helps you to communicate your needs with professionals, understand your rights and look after your wellbeing.

It also explains the steps to take if you need to challenge a decision or raise a complaint about a particular service:

[carersuk.org/self-advocacy](https://carersuk.org/self-advocacy)

Versions of the guide are available for England, Wales (in English or Welsh), Scotland and Northern Ireland.





Across the UK today 5.7 million people are carers – supporting a loved one who is older, disabled or seriously ill.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We're here to make life better for carers.

Carers UK 20 Great Dover Street, London, SE1 4LX

T 020 7378 4999 | E [info@carersuk.org](mailto:info@carersuk.org)



@carersuk



/carersuk



/carers-uk



@carers\_uk



@carers\_uk

Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London SE1 4LX.

Publication code: UK9069\_1123 | © Carers UK, January 2024

**[carersuk.org](https://carersuk.org)**