



# Why it is never too early for parent carers to think ahead.

Guided support for parent carers and families for when their child turns 16 years of age.



**It is never too late nor too early to start conversations with your family and with professionals.**



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# Introduction

## What is this guide and why the need for it?

This guide is intended to provide information and advice around the possible impacts upon parent carers and their families when their child turns 16.

- Parent carers and their families will be faced with a new array of legislation and rights that will apply to a child with a disability.
- Between the ages of 16-18, parent carers, their child(ren) and their family will be making
  - At 18 a child becomes an adult at which time they may be able to make their own decisions.



### Placing Parent Carers and their family at the centre

It may feel daunting and confusing for some parent carers and their family, to understand what decisions need to be made during this period and why.

- By outlining the key milestones, it may help parent carers and their family to be aware and therefore prepared, for the impact of those milestones upon themselves.



### **How to use this guide.**

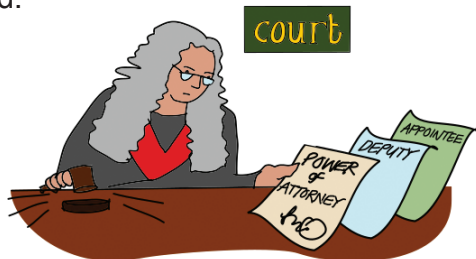
- This guide is for you to own.
- It provides:
  - suggested timeframes for you to start having conversations about the changes ahead.
  - suggestions as to whom you should be having those conversations with.
  - It gives you permission to reflect and act upon what you need to do personally when your child becomes an adult.  
Space has been left for you to make notes so you can record information that is important and relevant to you

**“There’s a lot of information I hadn’t thought about.” Parent carer.**

## **Section 1 - Finances, benefits, and associated benefits.**

As a parent carer you may have had to manage some of your child’s finances and benefits. However, the law assumes that when your child turns 18, they have the capacity to make their own financial decisions, unless they are not able to do so. If this is the case certain legal routes will have to be taken to appoint someone else to manage their money.

You may have also been used to certain other benefits becoming integrated into your household income or lifestyle. However, this may well change when your child turns 16, so you will need to ensure you know how those changes will affect you and your household.





## **1.1 Making Financial Decisions as a Parent Carer**

Most parent carers become appointees when the person they care for is still a child.

### **What is an appointee?**

- An appointee is put in place when someone finds they are unable or no longer able to manage their own Department of Work and Pensions (DWP) benefits claim.
- The appointee's role is to claim all benefits necessary for that person and to ensure the person's bills are paid.
- Associated benefits such as Personal Independence Payment (PIP) could well be claimed by the parent carer on behalf of their child.

### **What happens when someone turns 18?**

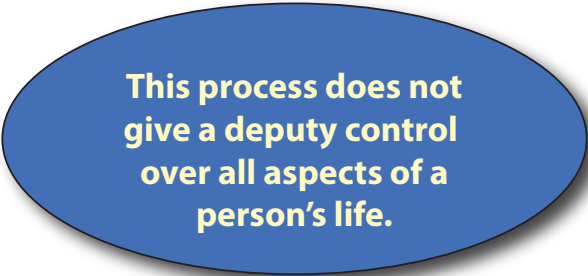
If that person has capacity to manage their finances, even if it is with support:

- the parent carer appointeeship should be rescinded (cancelled) by informing the Department of Work and Pensions.
- If that person does not have capacity to manage their finances a parent carer can apply for Deputyship.

## Deputyship

An application must be made to the Court of Protection for a deputy to be approved.

- Appointeeship needs to already be in place before this application is made.
- The deputy's role is overseen by the Court of Protection.
  - The application process is lengthy.
  - The court decides and approves the nominated deputy.



**This process does not  
give a deputy control  
over all aspects of a  
person's life.**

## Power of Attorney

Applied for by the person themselves, who at the time has capacity to make decisions.

- The person will decide who will be their court appointed attorney.
- The court appointed attorney takes over management of finances and/or health and welfare at such time that the person is deemed to have lost capacity, which may be permanent or temporary.

- Power of attorney is not an applicable process for somebody who does not have capacity.

### **Where can I find more information?**

For more detailed information go to the Government website [www.gov.uk](http://www.gov.uk)

### **Use the following key words to search**

- Become an appointee for someone claiming benefits, deputyship.

### **Other helpful places to look for information.**

- [www.peoplefirstinfo.org.uk](http://www.peoplefirstinfo.org.uk)
- <https://www.peoplefirstinfo.org.uk/media/5742/mca-easy-read.pdf>

## **1.2 Keeping your finances separate from your child's.**

As a parent carer for your child, you should ensure you keep your own finances separate from your child's. Once a young person reaches the age of 16, they can claim Personal Independence Payment (PIP) in their own right. It is for them to decide what the money is spent on. Therefore, by setting up a bank account in your child's name you can ensure any benefits or financial support your child receives does not get included in your household income.

## **1.2 Changes in benefits and any other associated benefit changes.**

When your child turns 18 (and in some instances 16) benefits and associated benefits that you and your child receive may well impact upon the benefits you can claim, the home you live in and use of a mobility vehicle.

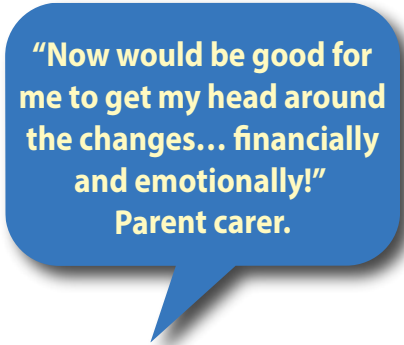
### **Benefit Changes**

The following benefits are just examples and not an exhaustive list of where those benefit changes could well affect you.

- When your child turns 16, Disability Living Allowance (DLA)/Personal Independence Payments (PIP) - at renewal DLA will be reassessed as PIP.
- Child benefit
- Universal credit
- Carers allowance
- Carers credit
- Council tax reduction
- Housing benefits

## **What can I do?**

- Take time to consider any financial benefits you or your child receive so you can ensure you know what provisions you need to plan for.
- Speak to a benefits expert to discuss any benefit changes by contacting your local Citizens Advice Bureau.



**"Now would be good for me to get my head around the changes... financially and emotionally!"  
Parent carer.**

## **When should I start having these conversations?**

As soon as possible. Your child should be aware of their finances.

## **Where can I find more information?**

For more detailed information go to the Government website [www.gov.uk](http://www.gov.uk)

## **Use the following key words to search**

- Child benefit
- Universal credit
- Carers allowances
- Carers credit
- Housing benefits
- Council tax reductions

### **1.3 Thinking about the house you and your family live in and any associated benefits being claimed.**

If your house has been provided to you and your family because it meets the care needs of your child, when or if your child permanently moves out of the house your housing provider may want to offer the house to another family with caring requirements. You will therefore need to seek alternative accommodation. You will also need to consider the impact upon the housing benefits and council tax reductions you can claim when your child turns 18 and/or permanently moves away from the home.



## What can I do?

- Before your child turns 18 speak to the relevant professionals about any changes to Council Tax Payments and Housing Benefit Claims that could occur once your child turns 18 and/or moves out of the home permanently.
- Speak to your housing provider to find out what your options are if/when your child permanently moves out of the home.

## When should I start having these conversations?

You should be having ongoing conversations especially if your child has said they want independence away from the home.

## **Where can I find more information?**

If you live in Monmouthshire and want to know more about Council Tax, go to

[\*\*www.Monmouthshire.gov.uk\*\*](http://www.Monmouthshire.gov.uk)

### **Use the following key words to search**

- Council tax.
- Help with council tax.

Contact your local housing provider as soon as you think your circumstances are going to change.

You can always talk to someone in the Housing Support Gateway at [\*\*www.Monmouthshire.gov.uk\*\*](http://www.Monmouthshire.gov.uk)

### **Use the following key words to search**

- Housing Support Gateway.
- Housing benefits.

For more detailed information go to the Government website [\*\*www.gov.uk\*\*](http://www.gov.uk)

### **Use the following key words to search**

- Local Housing Allowance.

Other useful organisations

[\*\*www.workingfamilies.org.uk\*\*](http://www.workingfamilies.org.uk)



**Use the following key words to search:**

- Advice for parents & carers.
- Benefits.
- Tax credits.



#### **1.4 Mobility vehicles and the impact upon you when your child turns 16.**


If your child has a car through the Motability Scheme and you and/or family members have been the main drivers of your child's car, from the age of 16 (if they receive or have applied for the enhanced rate of the mobility component of Personal Independence Payment (PIP)), your child may be able to drive their car for themselves.



**Remember the car is there to  
provide transport for the person  
with the disability.**

### **What can I do?**

- Consider your family's transport options.
- Talk to your child about whether they want, and who they want to add as a permitted driver to their policy. Discuss if they want support workers on the policy too.



**"Check that the vehicle  
can be driven by  
someone under 25."  
Parent carer.**

### **When should I start having these conversations?**

You should be having conversations well in advance of them turning 16, ideally as soon as they start to take driving lessons.

### **Where can I find more information?**

<https://www.motability.co.uk>

<https://www.gov.uk>

## **Use the following key words to search**

- Motability.
- Eligibility.
- Help if you have a disabled child.

## **1.5 Paying for Care – The Impact upon you when your Child Turns 18**

Under the Social Services & Wellbeing Act 2014 (Section 5) Local Authorities cannot charge children under 18 for the care that is provided to them. However, at 18 your child will be classed as an adult and any services provided to them may be chargeable.

### **When Care is Provided through Direct Payments**

Direct Payments (DP) may change when your child turns 16 or 17. At 16 or 17 your child may have the legal right to decide how their care package is managed, if they can manage them (this would be in conjunction with and decided by your Local Authority).

If someone lacks the mental capacity to manage their direct payment

- An appointed 'suitable person' will manage the direct payments on their behalf.

### **When should I start having these conversations, and what can I do?**

On the lead up to your child's 16th birthday

- Speak to a social worker as to how these changes will impact upon you, as a carer.
- Speak to your child about how these changes will affect both of you.



**Where can I find more information?**

[www.socialcare.wales](http://www.socialcare.wales)

[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)

**Use the following key words to search**

- Direct payments.
- Direct payments guide.
- Direct payments carers help and support.
- Charging and financial assessment.
- Social Services and Wellbeing Act 2014.

## This image shows a full page of a handwriting practice worksheet. It consists of multiple sets of three horizontal dashed lines, providing a guide for letter height and placement. The lines are evenly spaced across the entire page, leaving ample room for writing practice. There is no text or other markings on the page.

## Section 2

### Being prepared for how decisions are made on behalf of your child.


It can be a big part of your life and your family life, if you have had to advocate or make decisions on behalf of your child. There will come a time however, when you, your child and professionals will need to consider who will be best to make choices for your child. Legislation will also state who has the power to make those decisions so being aware of what the law says will help you prepare and plan.



#### 2.1 The health care decisions you can make, on behalf of your child, when they turn 16.

Under the Mental Capacity Act (MCA) it is assumed that an adult (aged 16 or over) has full legal capacity to make decisions for themselves unless it can be shown that they lack capacity to make a decision for themselves at the time the decision needs to be made. The Act ensures decisions made are in someone's best interests.

- If it is deemed that your child does not have capacity to make their own decisions, then the health professionals should assess and record this and the family should go to the Court of Protection to get a deputyship for their child so they can make health decisions for them post 16. A family lawyer may be best to advise on this.
- Start having ongoing conversations with your GP and Healthcare professionals when your child is around 16, so you know when and to whom your child's healthcare support is transferred into adult healthcare.
- If you do not have a social worker supporting you, you might want to consider contacting your local authority so that you can receive the appropriate support to guide you through this process.



**"It reminded me I still  
need to sort out health  
stuff."**

**Parent Carer**

### **What can I do?**

- Put plenty of time aside to plan, so you can have the right conversations with the right healthcare professionals and with your child.

## **When should I start having these conversations?**

On the lead up to their 16th birthday.

## **Where can I find more information?**

[www.gov.uk](http://www.gov.uk)

[www.mind.org.uk](http://www.mind.org.uk)

## **Use the following key words to search**

- Mental Capacity Act.
- Mental Capacity Act - Health and Welfare Decisions.

## **2.2 Understanding Deprivation of Liberty Safeguards (DoLS).**

DoLS is a legal process which provides protection for people aged 16 or over, who lack mental capacity to consent to their care and treatment, and therefore can be deprived of their liberty. DoLS aims to put the wishes of the individual concerned at the centre of all decision-making. There will be an explicit duty to consult those caring for the person and with those interested in the person's welfare.

## **What can I do?**

Have a conversation with a social worker or relevant professional so that you are informed as to whether DoLS is applicable to your caring circumstances.

## **When should I start having these conversations?**

When your child is approaching 16 years of age.



## Where can I find more information?

For more detailed information go to the Government website  
[www.gov.uk](http://www.gov.uk)

Use the following key words to search:

- Deprivation of Liberty Safeguarding.

## 2.3 Understanding your role in the educational & employment choices made by or for your child.

As a parent it is natural to want to be involved in the choices your child makes, especially about the next steps they take as an adult. Whatever employment or educational choices they make, if your child has capacity, it is their decision to make, because it is what is important to them – not to you as a parent carer.



### What can I do?

- Have these conversations as early as possible with your child, preferably before they turn 18.
- You will also need to consider together how at 18 they will get to and from school/work and how their transport will be paid for. As an adult they may not have access to funded transport.
- Talk to the school/college so you are all clear about where your involvement does/does not lie when your child turns 18.

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## Section 3

### Why it is important to think about you, and how you can prepare for the changes ahead of you.

When you have spent a lot of your time thinking about and making choices on behalf of your child you care for, it can be difficult to think about yourself. It can also be difficult to think about or even recognise that changes will happen as your child gains more independence. The choices you used to make on behalf of your child could change once they reach 16 years of age.



#### 3.1 Your Rights as a carer

When your child turns 18 or even before that, it may help to discuss how the changes will affect you as a carer and your caring role. Even if you do not regard yourself as a carer, Welsh legislation (Social Services and Wellbeing (Wales) Act 2014) recognises that when someone provides care for a disabled child or adult they are regarded as a carer.

#### What can I do?

- You could ask social services for a carer's needs assessment, or a re-assessment of your carers needs.

- Do not be put off by the word “assessment”, as a carer’s needs assessment affords you the opportunity to have a conversation with a social care professional about what matters to you.
- You might also want to consider how the caring role will continue in the home, especially if your child chooses to seek care from someone else.
- Use this as an opportunity to explore your options.

### **Where can I find more information?**

[www.monmouthshire.gov.uk](http://www.monmouthshire.gov.uk)

[www.carersuk.org/wales](http://www.carersuk.org/wales)

### **Use the following key words to search:**

- Carers Assessment.
- Looking after someone.

## **3.2 Recognising emotions when your child transitions into an adult**

From the age of 16 onwards, when your child is transitioning through to adulthood at 18, it may be difficult to foresee how the dynamics of your parent/child relationship may change. During this period of transition many families, and none more so than parent carers may well feel a range of emotions. Knowing this is normal may help you.

Even though in the eyes of the law a child becomes an adult at 18, they are still your child. It is also important to remember that siblings might be feeling similar emotions too during this period.

Try and remember that emotions and feelings come in different packages, and how you feel is personal to you and family members.

### **What can I do?**

- Talk to someone you feel comfortable with about how the changing situation makes you feel.
- Take time to explore what options for support are there for there for you



### **When should I start having these conversations?**

Anytime that you feel is right for you.

### **Where can I find more information?**

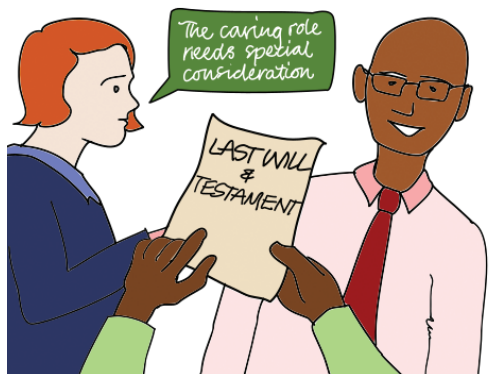
Different parent carer groups can change over time so rather than including specific groups here, simply search the internet using the following key words as guidance.

- Parent carer groups
- Parent carers (type in the locality you are seeking support from e.g. Monmouthshire, Gwent etc)

For dedicated support for sibling carers, please visit <https://www.sibs.org.uk/>

### 3.3 Why it is best to not avoid the difficult conversations

It may seem the best option is to avoid difficult or awkward conversations because you do not want to think about them. However, having difficult conversations as early as possible allows you to put considered and thought-out plans in place.



#### **Making a Will & Lasting Power of Attorney**

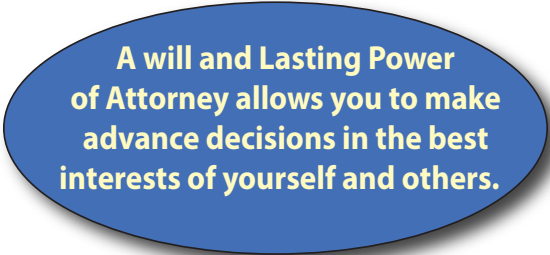
In the absence of a will, important and legally binding decisions could fall to family members, friends or professionals. Putting something in writing and making it a legal document allows you to make provision for the diversity of needs within your family when you are no longer alive.

A lasting power of attorney (LPA) is a legal document that lets you (the 'donor') appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf. This gives you more control over what happens to you if you have an accident or an illness and cannot make your own decisions ie you 'lack mental capacity'

**"It's reminded me  
that I still need to  
re-do my will."  
Parent carer**

## **What can I do?**

- Put plenty of time aside to think about what is important to you.
- Think about what provisions will need to be in place when you are no longer around to provide care.
- Seek legal advice from someone who understands how the caring role needs special consideration when drawing up a will.
- Research and if need be, seek legal advice about drawing up a Lasting Power of Attorney



**A will and Lasting Power of Attorney allows you to make advance decisions in the best interests of yourself and others.**

## **When should I start having these conversations?**

As soon as possible – consider making a will as early as possible in your child's life

## **Where can I find more information?**

[www.gov.uk](http://www.gov.uk)

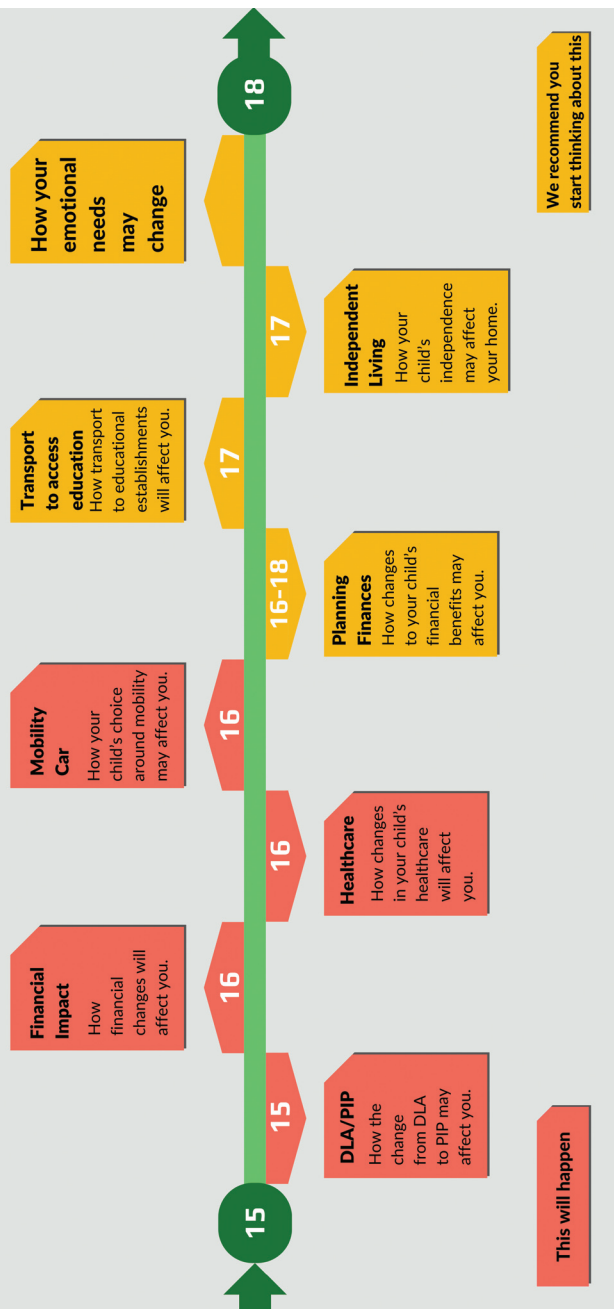
## **Use the following key words to search:**

- Writing your will.
- Last power of attorney.

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## The changes for you as a parent carer to consider



**Produced:** August 2024, in partnership with Monmouthshire County Council, Monmouthshire Carers Network, All Wales Forum and parent carer representation.

All websites were correct at time of going to the press and may subsequently be subject to change.

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