



## Family Ambassador Service

# Parent information for over 17s



This information aims to support parents whose children are both needing highly specialised (often inpatient) CAMHS care, and are approaching adulthood.

Please use the website below to ensure you have the most up to date version of this document.

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# Parent information for over 17s

## Introduction

This information aims to support parents whose children are both needing highly specialised (often inpatient) CAMHS care, and are approaching adulthood. It is written by Family Ambassadors, who themselves have children needing Tier 4 CAMHS care and navigated the path to adulthood.

It is not intended as advice and serves to introduce topics with links for more information.

Child refers to 'your child' or 'young person' throughout this document and 'parent' refers to 'parent or carer'.

## 1 Ensure you can continue to act for your child once they become 18 (with your child's consent)

Once your child is 18, most education and health services will communicate directly with them. If your child would prefer for you to act for them sometimes (for example arrange a GP appointment) the service will need to have written consent from your child on file.

It is advisable, where you can, to have a conversation with your child to determine their wishes.

Continued support from you doesn't mean they cannot have autonomy – more that, when they are feeling overwhelmed, you can make and take calls on their behalf, order prescriptions, ask for information, liaise with education providers/health/social care and so on.

Things to consider (if your child would like your continued support):

- Ask your GP and any other health and social care services for a copy of their 'consent to share information form', complete it with your child and return the completed form to them, keeping a copy for yourself.
- If your child is going to further or higher education, ensure that appropriate sections of the admission and application forms are ticked with agreement to share information. This includes UCAS and student finance if your child is going to university.

It is so much easier to have these in place in advance than trying to arrange something when your child is struggling.

## 2 Registers for Children and Adults with Additional Needs and / or Disability

### 2.1 Additional Needs Register

Every Local Authority has a Children's Disability and Additional Needs Register (sometimes known as a Disabled Children's Register). The registers are free to join and completely voluntary. You can use this link to find your local council <https://www.gov.uk/find-local-council>.

### 2.2 GP Register

If your child has a learning disability, ask your GP to add them to the [learning disability register](#). By joining the register your child will get extra support when visiting your GP, and longer appointments. Those over 14 should also get an [annual health check](#).

### 2.3 Dynamic Support Register (Autism and / or Learning Disability)

The NHS has a system for preventing unnecessary admissions to hospital for people with learning disability and / or autism. There are 2 parts to this, the Dynamic Support Register (DSR) and Care, Education and Treatment Reviews (CETRs). If your child has autism, or a learning disability, and is in a CAMHS unit, then it is helpful for them to be placed on the DSR. The DSR has a colour coded system:

- Red is for people who are at high risk of going into hospital straight away.
- Amber is for people who are at high risk of going into hospital if they do not get the right care and treatment soon.
- Green is for people who are having their risks managed well at home.
- Blue is for people who are already in hospital.

If your child is deemed at high risk they may be allocated a Key Worker to help to identify the services they need, and to access these services.

If, following discharge, your child's needs change it is important that the team holding the DSR are notified so a re-assessment can take place. In some areas parents can refer their child for this reassessment. In other areas you will need a member of the health or social care team to make this referral. The purpose of the reassessment is to identify provision that should be in place to prevent an admission to hospital.

This system is new and evolving, however, [your local authority website](#) should have a link to the service.

## 3 Financial Help

For all areas of financial support your local benefits office may be able to advise. These tend to be part of [your local council](#). It might be worth asking if they have a designated Young Person's Advisor, as some benefits offices have one of these.

### 3.1 Non means-tested disability benefits: Personal Independence Payment (PIP).

It is very likely that your child will be eligible for PIP if they are an inpatient.

You can call 0800 917 2222 to be sent a form. Useful to know:

- Allow time – it's not a quick call.
- If appropriate request to be an 'appointee' so you can fully support the application directly and make calls on their behalf.
- You will be asked for the following during this call:
  - contact details (use your details if you are to be an appointee)
  - date of birth
  - National Insurance number of the young person
  - bank or building society account number and sort code
  - doctor or health worker's name, address and telephone number

There is more information about PIP [here](#).

PIP should not be stopped when your child is in hospital. If a child is admitted to hospital before the age of 18, and then stays in hospital care post 18, then PIP should continue until discharge no matter how long this period is. [Contact](#) and other disability/benefits sites explain the rules further.

Fightback4justice is a good source of help for benefits: [fightback4justice.co.uk](https://fightback4justice.co.uk). Others can be [found here](#).

### 3.2 Carer's Allowance

If your child is in receipt of PIP, and your earnings are £139 (amount correct for 2024) or less, per week after tax, National Insurance and expenses, you may be entitled to carers allowance. Carers allowance is £76 per week (in 2024) plus National Insurance credits. More information is [here](#) and [here](#).

### 3.3 Child benefit for children remaining in education age 16-20

Child benefit can remain until the age of 20 if the child continues with education at A level equivalent ([level 3](#)) or below. Child benefit automatically stops on 31 August on or after your child's 16th birthday if they leave education or training. You need to let the Benefits Office know your child is remaining in education for it to continue, details on how to do this are

[here](#). If your child is not well enough to engage in 12 hours of more per week of education, they are likely to be eligible for universal credit – see below.

### 3.4 Universal Credit

In a few circumstances 16-18 year olds are entitled to Universal Credit (UC). For example, if your child is not in education, employment or training (e.g. an apprenticeship) because they are unable to work due to ill health. Those who do not have parental support, for example, who do not live with their parents and are not under local authority care also may be eligible. You can find out more on the DWP website [here](#).

Contact have more information [here](#).

Turn2us share information [here](#).

### 3.5 Employment Support Allowance

In some circumstances, such as when you child has a learning disability and / or autism, it may be right to make a “credits only” claim for new style Employment Support Allowance (ESA) which will award credits towards a pension.

For both UC and ESA ‘Contact’ (previously Contact A Family) have helpful information [here](#). You can also use their helpline for advice 0808 808 3555.

### 3.6 Help with NHS Costs - Prescriptions

Post 18 your child will need to pay for their prescriptions in most cases. Exceptions to this are where:

- they are eligible for Section [117 aftercare \(see section 4\)](#), then they may be eligible for free prescriptions for their mental health conditions.
- they receive income-related Employment and Support Allowance or [Universal Credit](#) and meet the free prescription criteria.
- they are under 20 and dependent on someone receiving income related benefits.
- they have epilepsy which needs continuous anticonvulsive therapy

See here: [Free NHS prescriptions | NHSBSA](#) for all eligibility.

If your child needs 4 or more prescriptions in 3 months, or 12 or more prescriptions in 12 months, it may be cheaper to buy a [pre-payment certificate](#) for their prescriptions. In 2024 these cost £31.25 for 3 months or £116.60 for 12 months. They can pay in instalments for the 12-month certificate.

### 3.7 Other NHS Costs

Free travel for NHS care (but not for visiting). If you are in receipt of means-tested benefits, such as UC, or ESA, you are entitled to have travel costs re-imbursed in some circumstances. You would need to take evidence of your eligibility and receipts for travel to the Cashiers’ office – [more information is here](#).

NHS Low Income Scheme: help with NHS costs including prescriptions, dental, eyecare, healthcare travel. You can apply for the scheme as long as your savings, investments or

property (not including where you live) do not have savings of more than £16,000. You will need to complete an HC1 form, more information is here: <https://www.nhs.uk/nhs-services/help-with-health-costs/nhs-low-income-scheme-lis/> or you can phone: 0300 330 1343 for a form.

### 3.8 Free travel passes

You can apply for a disabled person's bus pass or railcard if you have a condition that makes it hard to get around. You don't need to have a physical health problem - people with learning disabilities can apply too. Someone else can apply on your behalf, if you need help with the application. You'll be able to travel for free by bus, or get 30% off your train tickets.

Contact your local council to find out who issues disabled bus passes in your area as part of the English National Concessionary Travel Scheme. [Apply for a disabled person's bus pass - GOV.UK \(www.gov.uk\)](#). [A disabled persons' railcard can be applied for here.](#)

### 3.9 Free entry to attractions and facilities

Some local authorities are signed up to the Max Card scheme: <https://mymaxcard.co.uk/about-us/>. Families can use their Max Card at venues across the UK to get free or discounted admission and young people up to 25 years old are eligible.

Most attractions allow a carer in free to accompany a person with additional needs. Evidence of PIP or DLA is usually all that is required.

Entry at facilities (such as swimming pools and local authority gyms) can be free or at a reduced cost for carers. Typically, you would need proof of address with ID and evidence of the disability benefits of the person you care for. Each local authority may have different rules, but it may be worth enquiring.

## 4 Section 117 Aftercare

If your child has been sectioned under Section 3 of the Mental Health Act (and other cases including sections in the forensic sector) they have a legal right to support via 'Section 117 Aftercare'. This is funding that can be used to support their care after they leave hospital. It can cover things like healthcare, social care, activities that are therapeutic to the individual and supported accommodation.

Section 117 of the Mental Health Act says aftercare services as those which:

- a) meet a need that arises from, or relates to, your child's mental health condition, **and**
- b) reduces the risk of their mental health condition getting worse, and them having to go back to hospital.

Section 117 support is individualised and aimed at ensuring continued recovery from their mental ill health.

Section 117 aftercare should be agreed as part of discharge planning, although decisions around this can continue post discharge. The inpatient team, community team, and, where applicable, children's social care should all contribute to this plan. If it hasn't been mentioned to you, you can raise it in advance of discharge with your child's Responsible Clinician at Care Programme Approach (CPA) meetings, and make sure it is included in the CPA notes.

The social care elements of the aftercare plan will be reviewed by a social care panel to ensure that any parts that can be met by available community services are considered before the package is funded.

Section 117 aftercare can be implemented at any time post discharge if the requirement/need relates to the reason for detention under the MHA.

Your child's right to section 117 aftercare doesn't end until their care team agree that they no longer need that support.

More information is [here](#).

## 5 Access to work

The Access to Work Scheme can help you get or stay in work if you have a physical or mental health condition or disability. The support you get will depend on your needs. Through Access to Work, you can apply for:

- a grant to help pay for practical support with your work (including travel costs if you are unable to use public transport)
- support with managing your mental health at work
- money to pay for communication support at job interviews.

Eligibility: For these types of support, you must:

- have a physical or mental health condition or disability that means you need support to do your job or get to and from work
- be 16 or over
- be in paid work (or be about to start or return to paid work in the next 12 weeks)
- live and work (or be about to start or return to work) in England, Scotland, or Wales.

As well as national schemes there are often local ones to support those in work, struggling to get work, or struggling with motivation to be occupied in the day. The local mental health social worker can help further.

More information is [here](#).

## 6 Education

Many young people with mental health conditions miss out on education because of their illness or disability.

In most cases, the degree of mental illness those in inpatient CAMHS experience means they meet the criteria for disability. Their difficulties in managing mainstream education usually mean they meet the criteria for Special Educational Needs (SEN). Many children with SEN have average or high levels of academic ability; this does not exclude them from support.

For some, reaching 18 and not thinking about education again is a blessing. However, others can feel as though their educational needs have been overlooked and would like to have them supported, to achieve at least an English and Maths qualification. For others achieving to their full level of ability is important to them, and they may need more time and / or support to enable this.

It is often important to ongoing recovery that their educational needs are considered and that both you and your child are aware of the options available. This can be through an Education, Health and Care Plan (EHCP), or it may be via a lower level of 'SEN support'. Both levels of support can be delivered through schools (for example by repeating Year 13 with higher levels of support) or through college.

Education up to level 3 (A level or equivalent) is available to young people up to the age of 25 via an EHCP. So, if, due to illness or disability, they have not been able to access education for some time during adolescence – even if this is for several years, it may still be possible to be supported to access education post 18.

The [SEND Code of Practice](#) outlines details of provision that should be made up to the age of 25. More sources of information relating to education is [here](#).

### 6.1 Education – EHCP – up to age 25 and up to Level 3 study/Qualification.

Your child may be entitled to an EHCP specifying and funding education until the age of 25. Your local SENDIASS can help. You can find their details by using this link: [Find your local IAS service \(councilfordisabledchildren.org.uk\)](http://councilfordisabledchildren.org.uk)

If an EHCP is already in place, your child's needs relating to transition to adulthood MUST legally be discussed at Annual Review from Year 9 onwards. [Chapter 8 of the SEND COP](#) outlines the responsibilities of your Local Authority in relation to preparation for adulthood.

If an EHCP was in place before admission a review of the 'needs' (section B) and 'provision to meet needs (sections F) is probably required. The aim of this would be to ensure that it properly reflects all current needs and provision needed.

## 6.2 College

This section does not apply to university level education. See [6.2 University - Disabled Student Allowance](#) for support in university.

Your child can be supported in college with 'SEN support' or if their needs are greater, via and EHCP.

Colleges have a duty to support the additional needs of their students, following the same laws that apply to schools. They are often used to supporting young people with health difficulties that have left them feeling as though they are falling behind their peers.

[Chapter 7 of the SEND Code of Practice](#) outlines the responsibilities of Further Education / post 16 places of education. It states, "Where a student has a learning difficulty or disability that calls for special educational provision, the college **must** use its best endeavours to put appropriate support in place" (p114 7.13).

## 6.3 University - Disabled Student Allowance

EHCPs do not include this level of study.

DSA is non-means tested and does not need to be paid back. Funding and support can be offered for:

- specialist equipment, for example a computer if you need one because of your disability
- non-medical helpers
- extra travel to attend your course or placement because of your disability
- other disability-related study support, for example having to print additional copies of documents for proof-reading.

You can apply for Disabled Students' Allowance (DSA) if you live in England and [have a disability that affects your ability to study](#), such as a:

- specific learning difficulty, for example dyslexia or ADHD
- mental health condition, for example anxiety or depression

## 7 Support for Carers

### 7.1 Carers Assessments

If you care for someone, you can have an assessment to see what might help make your life easier. This is called a carer's assessment and is covered by Section 10 of the Care Act (2014) if caring for those over 18 and the Children and Families' Act (2014) if under 18. A carer's assessment is free and anyone over 18 can ask for one.

To make a request, contact your child's social worker or, if there is one the social worker attached to their Tier 4 service. If your child does not have access to a social worker, you can approach your local children's social care services to request one. The link to 'Contact' below sets out the law and example letters.

A carers' assessment might result in recommendations such as:

- someone to take over caring so you can take a break
- gym membership and exercise classes to relieve stress
- help with taxi fares if you don't drive
- help with gardening and housework
- training how to lift safely
- putting you in touch with local support groups so you have people to talk to
- advice about benefits for carers
- there are small additional benefits such potentially free flu jabs.

A useful summary of this and how to access an assessment can be found on the [Contact site \[hint – scroll down the page and take a look at the factsheet\]](#). The NHS information is [here](#).

See [section 3.2](#) for carers allowance.

### 7.2 Child in Need Assessments for those under 18

Some families may benefit from a Section 17 (Of the Children Act 1989) assessment of the family's needs – in these situations wider support may then result, such as carer support in the evenings, travel training and supported activities during holidays.

### 7.3 Other Sources of Support

You may wish to register as your child's carer with your GP. More information about the benefits of this and a template letter can be found at the [Carers UK website](#).

More information for carers can be found at the [Carer's Trust website](#), including the 'Triangle of Care' which may help with more information about your role in your child's care as a carer.

## 8 CAMHS inpatient to Adult Mental Health Services FAQ

The NHS guide for moving to adult services can be found [here](#). Local services may also have guides and information for example [here](#). In preparation for meeting the new teams you might like to prepare a brief timeline / history document which picks out the key events per academic year. This way, accurate information can easily be shared and you and your child will need to repeat information less frequently. An example is below, [here](#).

### 8.1 How are the decisions made, and who is involved?

If the need for specialist mental health services after reaching 18 years seems likely, meetings to discuss the best ongoing care for your child are held. These start soon after your child is 17 and a half (depending on their admission date and overall condition). They will include staff from both community and inpatient CAMHS and other members of the multidisciplinary team.

Wherever possible a model of care based in the community will be planned. For a few children ongoing care in an inpatient setting will be needed.

Your child should always be involved in the planning, information should be developmentally appropriate for them and they should have a named worker who is responsible for coordinating their transition care and support ([NICE Guidance 2023](#))

Unless there is a full care order, and where the child consents, you should be fully involved in planning the next steps for their care and in planning the detail in the care package.

Care teams may make assumptions about your capacity to care and your ability to meet your child's mental health needs as they move into adulthood. It is important to share with your child's care team what care and support you can give to your child beyond their 18<sup>th</sup> birthday, and what you can't. This helps to ensure everyone is clear how, and by whom, your child's mental health needs are going to be met in adulthood.

### 8.2 Which inpatient service will my child go to?

Your child's history and present needs will be considered as well as the location of services. Some adult services are best suited for those with learning difficulties, others for eating disorders or general psychiatric presentations. Young adults often present with mixture of needs and so the most appropriate setting for the mixed presentation will be identified.

Where community support is advised this may look different to children's mental health teams. They may for example be supported directly by a psychologist, occupational therapist or a care co-ordinator.

### 8.3 When will my child be transferred?

It is likely that this will be within a period of time surrounding their 18<sup>th</sup> birthday, however the teams involved in caring for your child will do all they can to ensure it is not on their birthday.

## **8.4 What planning and preparation will take place for the transfer to inpatient adult services?**

Support, preparation and introductions should be made for your child to know more about their adult team. This may work differently for each service, however, it may be worth asking for a written version of this plan during CPAs when your child is over 17 ½.

## **8.5 Nearest Relative**

If your child will be in hospital under a Section 2, 3, 4 or 37 of the Mental Health Act (1983) the 'Nearest Relative' rules will apply. This is not the same as the more formal 'next of kin'. The nearest relative is another way of making sure that your child's rights are protected. More information can be found on the MIND website, [here](#).

## **8.6 What involvement will I have in my child's care? They have consented to my ongoing involvement in their care.**

The ward team will welcome your knowledge of your child's history and present needs. You can be involved in meetings and discussions about your child's care (if they consent to this) in a similar way that you do in the CAMHS service, but you may need to be pro-active in ensuring you are invited to these.

If you have developed [a timeline](#), please share this with the ward team.

Ward Rounds: these usually happen every week. If you are unable to attend, you can send in questions or information that you would like them to consider.

Care Programme Approach (CPA) meetings. You can attend, or send in information, in the same way you might for the ward rounds.

## **8.7 What involvement will I have in my child's care? They have not consented to my ongoing involvement in their care.**

If you are your child's Nearest Relative (see section 8.6), and they are cared for under a section of the Mental Health Act, then some information will be shared with you. More information [is here](#).

You can still share what you know about your child, their needs and the best ways to support them with the clinical team.

If your child hasn't consented to sharing information with you, the clinical team is able only to share information where there are significant changes or risks (for example if they require transfer to a general hospital for a physical health condition).

## **8.8 Advocacy**

The [CAMHS Family Survival Guide](#) and [MIND](#) and [NHS](#) have guides that explain about your child's rights to advocacy if they are detained under the Mental Health Act (1983). NICE Parent information for over 17s

guidance relating to Advocacy is [here](#). In some circumstances a solicitor can be offered to your child to help them to make decisions.

## 9 Laws and NICE Guidance

- Those with a long term, functionally impacting mental health conditions are disabled according to [The Equality Act 2010](#) and have rights under this act.
- Rights to an education (up to age 25) are specified in section 3 [Children and Families Act 2014](#). The [SEND Code of Practice](#) contains most of the information and is more readable.
- NICE Guidance: [Transition from children's to adults' services for young people using health or social care services \(nice.org.uk\)](#).
- This page specifies [NICE guidance related to Eating Disorders and transition to adult services](#): scroll to the bottom for a number of links relating to Eating Disorders.

## Appendix 1 - Timeline

You can use the format below to include a summary of issues / referrals per academic year. It is good to include all referrals that have been made (even if rejected) and the broad outcomes of these. Precise dates and details of appointments aren't needed. You don't need to look out letters and reports unless there are a few specific points you wish to clarify.

### Example 12-month entry for Year 8

**Education** Difficulties continued. Pressure from school to attend continued. Bullying got worse and by December she was rarely able to attend school due to anxiety and exhaustion. School referred to Social Services due lack of attendance, but no action was taken.

**Health** Self harm increased. Eating restrictions increased. Emma took an overdose of paracetamol in January and was assessed but then discharged from CAMHS with advice to use self-help resources. Seems depressed. Multiple visits to GP who wrote to school to explain absences.

**Social Care/other** Not engaging with other CYP in person but is hooked on social media and talking to other CYP who self-harm. We restricted the use of her phone, but her mood deteriorated, and she became very depressed.

### Current diagnoses and those being considered:

Include year of diagnosis, referrals made for assessment and provisional diagnoses (for example, Autism considered but too unwell for assessment).

### Preschool and reception 20xx- 20xx

**Education** for example, what went well, difficulties, extra support needed, education assessments, unmet needs relating to school and education.

**Health** for example referrals to speech and language, repeated infections, GP visits and referrals for anxiety, eating etc. Key hospital admissions and diagnoses.

**Social Care/Hobbies/Activities** include activities that have needed to stop due to ill health, difficulties and vulnerabilities socially and referrals / support to social services.

### Primary School Year 1 – Year 5 20xx- 20xx (add a section for each year group if a lot of difficulties presented in primary school).

**Education**

**Health**

**Social Care/Hobbies/Activities**

### Pre-transition Year – Year 6 20xx- 20xx

**Education**

**Health**

**Social Care/Hobbies/Activities**

### Year 7 20xx- 20xx

**Education**

**Health**

**Social Care/Hobbies/Activities**

### Year 8 20xx- 20xx

And so on...

## Version History

version	Date	
0.1	Sept - 26/10/23	Developed by Lara Barnish and extended/discussed with Denise Tenney, Tania Webb and Elizabeth Boughton
0.2	26/10/23	For consultation with the National Family Ambassador Team
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