

# **PARENT/CARER SUPPORT GUIDE**

## **CHILDREN AND YOUNG PEOPLE (CYP) SERVICES**



**MADE BY PARENTS/CARERS, FOR PARENTS/CARERS**

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# FOREWORD

*"Being a parent or carer of a young person with mental health difficulties can be a worrying, lonely place to be. Feelings of confusion, guilt, self-doubt, anger, fear, sadness – when our daughter became unwell and was referred to Children and Young People (CYP) Services, we felt all of these emotions and more. We felt lost at sea, drowning and not sure which way to turn for support.*

*The focus at CYP services is quite rightly the young person who is struggling. But as with any serious illness, the impact is felt by the whole family. We are the ones who are there, day in and day out. A mental health appointment might be one hour a week, but we are the ones supporting our loved ones for the other 167 hours of the week. Family is the biggest asset a young person has when battling emotional or mental health difficulties; parents and carers can play a vital role in their child's recovery. But it's no small task. Not only are we supporting our child with day-to-day practicalities and providing 24/7 emotional support, we are also having to navigate our way through school and emotional and mental health services, which can be frustrating and overwhelming. You might have other children too, who need your time and attention. It is exhausting, and it's no wonder that it can impact on our relationships, work, and the health and wellbeing of the whole family.*

*As parents we felt we needed more information and support. We searched high and low and found amazing charities and organisations that proved to be a lifeline for us. So many websites with useful information, forums where you can speak to other parents in a similar situation (invaluable!), phone lines to speak to people that 'get it', and parent courses to better understand our child's difficulties – all these things helped us in so many ways along our journey.*

*No family should feel isolated when they're going through one of the toughest experiences of their lives. That's why we've worked with CYP services and other parent/carers to create this guide. There is wonderful support out there - we hope this guide helps you to find the right support for you."*

*This guide is written by parent/carers, for parent/carers*

*Remember: You are not alone. You've got this.*

*Signed, the parents of a wonderful young lady x*

# A BRIEF INTRODUCTION TO CHILDREN AND YOUNG PEOPLE (CYP) SERVICES

## FIRST THINGS FIRST – UNDERSTANDING THE LANGUAGE!

There are so many different professionals and teams in Children and Young People (CYP) Services and there are so many acronyms and jargon used – it can be really confusing. With this in mind, we have worked with CYP services to develop a 'jargon buster' with common terms and acronyms. This is available on the Lincolnshire Partnership Foundation Trust (LPFT) website:

[www.lpft.nhs.uk/yp/lincs-jargon-buster](http://www.lpft.nhs.uk/yp/lincs-jargon-buster)



Children and Young People Services is the 'umbrella' term used to talk about a number of different services and teams. These include:

### Emotional wellbeing

- Healthy Minds Lincolnshire (HML)
- Mental Health Support Teams (MHST)

### Mental Health and Learning Disability

- Child & Adolescent Mental Health Services (CAMHS)

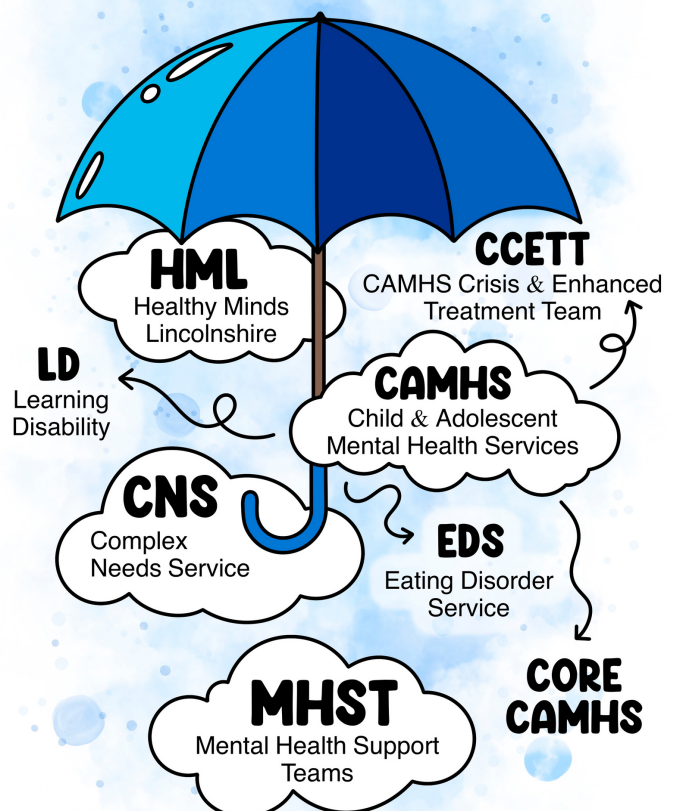
### Complex Care

- Complex Needs Service (CNS)

There is more information about each of these teams on the jargon buster on the LPFT website.

Though these teams support families in different ways, they work closely together to make sure they are providing the best support for you and your child.

## CHILDREN & YOUNG PEOPLE SERVICES



## COMMUNICATION IS KEY

Following an assessment in CYP services, your child will typically be assigned a practitioner; this is the person they will see and talk to, and hopefully build a good working relationship with. This may be a little different if your first introduction to CYP services is following a crisis incident, however you will still be given contact details for the treating team.

You will be made aware that your child's practitioner(s) is bound by confidentiality, and therefore cannot discuss certain information with you. As a parent/carer this can be really difficult to balance sometimes – you want your child to have that safe space to talk and don't want to compromise their therapeutic relationship with their practitioner, but you also understandably want to be involved. You may feel like you can't or shouldn't contact your child's practitioner(s) or team. **Well you most definitely can and should!**

As your child's main caregiver you are key in building a holistic picture of what is going on for them. Although your child's practitioner(s) cannot share certain information with you, they should still be more than happy to talk to you in the following instances

- To discuss how you can be involved in your child's care.
- If you feel your child might not present an accurate representation of how things are, and how they are really doing – you can provide some additional information to their practitioner.
- If something has changed and you are growing more concerned about your child and their wellbeing.
- You can ask about the support plan for your child, and advice in terms of risk management, what to do in a crisis situation etc.

## REASONABLE ADJUSTMENTS

Reasonable adjustments can be made for any child or young people in order for them to access LPFT CYP services, taking into account ages, cognitive ability, communication needs, and individual circumstance and need. If you think your child requires reasonable adjustments to access or engage in CYP services, then please let the treating team or practitioner know.



# WE WISHED SOMEONE HAD TOLD US SOONER...

**1** You can register as your child's carer by speaking to your GP surgery. If your doctor and surgery know you are a carer, they can support you with any physical or mental health issues related to your caring role and provide you with general information and advice.

**2** Carers First offer online help and support to carers, as well as 1-2-1 practical and emotional support in some instances. They can also guide you as to what is available your area, or whether you are eligible for additional assessment and support.

[www.carersfirst.org.uk/lincolnshire](http://www.carersfirst.org.uk/lincolnshire)



**3** Depending on the needs of your child/young person, you might be able to claim Disability Living Allowance (for under 16s) or Personal Independence Payment (over 16) for your child.

Claims are based on a person's needs rather than their particular condition or diagnosis. Disability Living Allowance (DLA) and Personal Independence Payment (PIP) are not means-tested, which means that how much you earn from your job has no bearing on the amount of DLA or PIP you receive.

*Please note CYP services do not typically provide bespoke letters of evidence to support these applications and cannot advise as to whether you are eligible to make a claim.*



[www.gov.uk/disability-living-allowance-children](http://www.gov.uk/disability-living-allowance-children)



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



**4** Juggling work and care can be very challenging, so it's important to find out about your employment rights, such as:

- The right to request flexible working
- The right to time off in emergencies
- Protection from discrimination
- The right to parental leave

[www.carersuk.org/help-and-advice/work-and-career](http://www.carersuk.org/help-and-advice/work-and-career)



- 5 As parents/carers, you can access LPFT's Recovery College, which runs lots of different educational courses ranging from different mental health conditions, to things like self-care and journaling, to specific courses for parents and carers.

*"It was nice that the tutors are carers or have been carers. In my experience, it makes all the difference having someone who knows the feelings that often accompany caring and long-term caring. I thought it was good it spoke about dread and guilt. These feelings are something I am very familiar with."*

[www.lpft.nhs.uk/our-services/adults/recovery-college](http://www.lpft.nhs.uk/our-services/adults/recovery-college)



- 6 Social, emotional and mental health is one of the broad areas of need for Special Educational Needs (SEN), and every school is required to have systems in place to identify children who are in need of support and to assess, monitor and secure appropriate support for any SEN they may have. Your child doesn't need a formal diagnosis for this to happen.

**Not Fine in School** is a parent/carer-led organisation. It has produced resources based on relevant government policies and guidance, to help parents and families to work with professionals to assess and then plan appropriate and timely support. It also has an active Facebook page, along with private Facebook communities you can join.

[www.notfineinschool.co.uk](http://www.notfineinschool.co.uk)



The **Independent Provider of Special Education Advice (IPSEA)** offers free and independent information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities (SEND). They have lots of useful information on their website, and have a helpline for any individual queries.

[www.ipsea.org.uk.co.uk](http://www.ipsea.org.uk.co.uk)



**Liaise** is Lincolnshire's Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS). They provide confidential and impartial information, advice and support to children and young people (0-25 years) with SEN and disabilities, and their parents and carers.

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



## THE BEST ADVICE WE WERE GIVEN...

**DON'T RUSH TO  
FIX IT, JUST  
LISTEN.**

*"As a parent, you're automatically geared to try and 'fix' any issues your child has. It's so hard seeing your child struggle and so it's natural that we just want to make things better for them. But mental health doesn't work like that. Once we stepped down from this mentality, and provided more listening space for our daughter, it created new lines of communications; she started opening up to us more and our relationship strengthened as a result.*

*Get practising your "mmhmm"s and your "that sounds really difficult"s – phrases like these show active listening, and help to validate your child's emotions - they yield more power than you can ever know!"*

*"The most useful advice I was given was, don't think that because a service is recommending parenting groups in relation to your child's condition that they think the problem is at home. It is to help you understand the condition or illness and to drip feed mountains of information to your child as and when they need help. It also empowers you and help you feel like you are back in control."*

**INFORMATION  
IS POWER**

**BEHIND EVERY  
BEHAVIOUR IS AN  
EMOTION**

*"We were asked to take a step back and think about why our child was behaving in a certain way. We realised that what we thought was anger, was actually fear. Understanding that was huge for us and our relationship. After that, we tried to meet their emotion rather than the behaviour. It definitely helped us keep calm at times, when in the past there probably would have been a big argument."*

*"The best bit of advice I was given was to not forget I had a relationship with my child outside of their mental health difficulties and the shared journey we were both going on. It's easy for it to consume you, but try and remember to spend quality time with your child, and the whole family (including siblings), doing things you all enjoy. It could be something simple like having a film night, playing board games, going for dog walks together. Try not to forget the importance of those things in bringing you both joy, bringing you closer, but also providing opportunity for them to communicate how they are feeling."*

**TRUST YOUR  
RELATIONSHIP**

**YOU ARE NOT  
ALONE**

*"The thing that helped me most was knowing that many of the emotions I felt were normal; other parents/carers who are going through mental ill health with their child experience overwhelming emotions too, but because isolation is often a part of that journey you just never get to hear those other validating stories. I didn't hear from any other parent/carer going through something similar until much later down the line. Also, supporting your child through mental ill health is a whole other experience to normal parenting. It's not a weakness to feel overwhelmed or to need support for yourself."*

*"When our daughter struggled with difficult emotions, she verbally lashed out at us. At first we thought we were doing something wrong, but then someone made us see that it was because we were her safe place. She wore a mask for other people; painting on a smile. When she came home she was exhausted from pretending that everything was fine, and so the mask dropped with us. The big emotions were saved for us, the people she felt safest with. Reframing it in this way was really helpful us as parents. We could empathise and understand a little more."*

**YOU ARE  
THEIR  
SAFE SPACE**

**DON'T  
COMPARE**

*"It is so easy to become disheartened if we feel our child is 'getting behind' or isn't doing other things that other children their age are. There are so many expectations on young people – from friends, family, school, society, and even us as parents or carers... But in reality there is no set timescale to life. They are on their own journeys, at their own pace, and that's ok."*

*"It can be really frustrating when you don't understand why your child is feeling a certain way, and you desperately want to reassure them. Our default is to think we know best, and we want our child to see things our way. But our experience and reality is not theirs; you don't have to agree to see another person's perspective. Validating your child's emotions and feelings is a really powerful tool."*

**HONOUR YOUR  
CHILD'S  
REALITY**

*"That sounds difficult."*

*"You seem really anxious about..."*

*"I can see that's really bothering you."*

**APPRECIATE  
TECHNOLOGY**

*"Talking isn't for everyone, it is so hard for some young people to share their most vulnerable thoughts out loud in fear of what we would think of them or how we would we understand. I learnt to appreciate technology, albeit it was sometimes the root of a disagreement! My son's mobile became key to part of our communication when he was feeling low, an exchange of texts allowed me in, it allowed my son to share his thoughts comfortably, above all he was talking to me. I now felt more in control to support him."*

*"Emotions can be very abstract for some young people and hard to navigate with the added physical sensations. I learnt to name emotions as my son experienced them to add context for him. I didn't realise how scary it felt for him when he couldn't name his emotion and why he was feeling this way. If he couldn't name it how could he tame it? I shared my own emotions and how this felt physically. I normalised emotions to ease his anxiety and not feel so alone with them, the message being it's ok, we all have them! In time this supported his understanding and the exploration of how to manage them."*

**TALK ABOUT  
YOUR OWN  
EMOTIONS**

# SELF-CARE

Your child needs you, but you can't support them fully if you are not supporting yourself; you can't pour from an empty cup. Self-care is so, SO important. Make sure you make time, even if it's just for five minutes each day.



# MY SELF-CARE INCLUDES...



## FINDING SUPPORT FOR YOU

It's tough parenting a child experiencing emotional or mental health issues. If you find it's impacting on your own mental health, please don't be afraid to ask for support for yourself.

If you are feeling low, anxious or stressed and think that talking to another person may help you cope you can call [LPFT Mental Health Helpline](https://www.lpft.nhs.uk/mental-health-helpline)

0800 001 4331 (open 24/7)



If you recognise that you are also struggling with your own mental health and are in need of help, you may be able to get support from one of our adult mental health teams. [Steps2Change](https://www.steps2change.nhs.uk) provides talking therapies for people with mild to moderate mental health conditions, such as depression, anxiety and post-traumatic stress disorder (PTSD). View the Steps2Change website to find out more:

[www.lpft.nhs.uk/steps2change/home](https://www.lpft.nhs.uk/steps2change/home)



# MORE USEFUL WEBSITES & HELPLINES

We found that most information and support was geared towards the young people experiencing mental health issues – what we really wanted was support and guidance for us as parents, to help us to navigate this unexpected journey. Below are some websites which we found to be particularly helpful in terms of information and support for parents/carers:

**Parenting Mental Health** empowers and supports parents and carers, to help create stronger and more resilient families. They offer emotional support services, events and training courses. Crucially, there is a 24/7 peer support network via a private Facebook group, where you can discuss things with other parents and carers who ‘get it’; it provides a safe place for us parents to vent, let off steam, but also ask for other people’s experiences and opinions.

[www.parentingmentalhealth.org/](http://www.parentingmentalhealth.org/)



**Young Minds** is a mental health charity which has useful, practical advice and tips on supporting your child on their website. This ranges from how to encourage your child to open up about their feelings, to navigating mental health services. There is lots of useful information on their website for parents and carers, and personalised support is available via the parents’ helpline, webchat and email services.

[www.youngminds.org.uk/parent](http://www.youngminds.org.uk/parent)



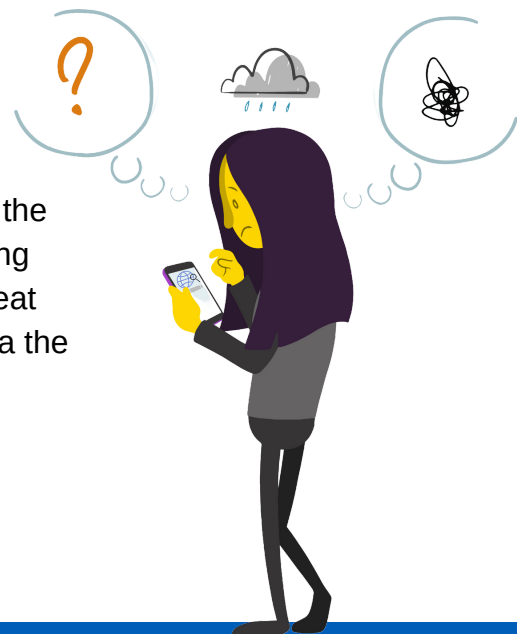
**Mind UK** is the UK’s leading mental health charity. Their website has lots of useful information and guides for parents / carers, including how to support your loved one, how to approach certain conversations, information on specific diagnoses or issues and tips on coping whilst caring for someone else.

[www.mind.org.uk/information-support/  
helping-someone-else](http://www.mind.org.uk/information-support/helping-someone-else)



**Papyrus** is a UK charity dedicated to the prevention of suicide and the promotion of positive mental health and emotional wellbeing in young people. There is a lot of useful information on their website, with great resources for you to download. Personalised support is available via the Hopeline telephone line.

[www.papyrus-uk.org](http://www.papyrus-uk.org)



**This May Help** is a website for parent/carers who have concerns about their child's mental health. The subjects covered on this website have been chosen by families and young people who have gone through their own mental health challenges.

[www.thismayhelp.me](http://www.thismayhelp.me)



**Lincolnshire Partnership Foundation Trust** has useful information on their website for young people but also for parents and carers to help make sense of what your child is going through. This includes jargon busters, and useful links to websites and resources.

[www.lpft.nhs.uk/yp/lincs-parents-and-carers](http://www.lpft.nhs.uk/yp/lincs-parents-and-carers)



## USEFUL HELPLINES

### **Young Minds Parent helpline - 0808 802 5544**

A free confidential helpline for detailed advice, emotional support and signposting. Available 9:30am - 4pm, Monday to Friday.

### **Papyrus Hopeline – 0800 068 4141 or TEXT 07860 039967**

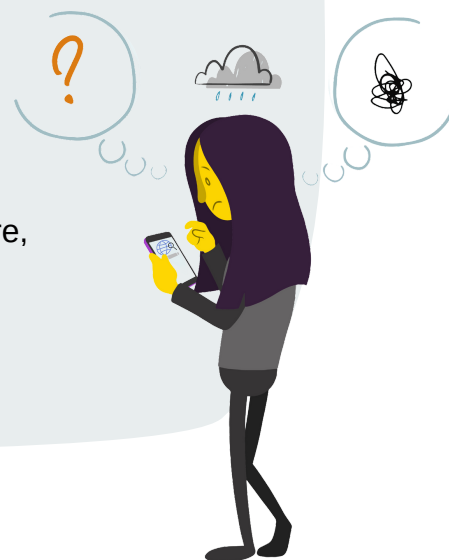
A free confidential helpline for any young person contemplating suicide, or parents / carers supporting a young person. Open 9am – midnight every day of the year (weekends and bank holidays included)

### **Mind Infoline – 0300 123 3393**

Provides an information and signposting service. Open 9am to 6pm, Monday to Friday (except for bank holidays).

### **Mind Legal Line – 0300 466 6463**

Provides legal information and general advice on mental health related law (e.g. mental capacity, discrimination, community care, mental health Act). Open 9am to 6pm, Monday to Friday (except for bank holidays).



**WE HOPE YOU HAVE FOUND THIS  
BOOKLET HELPFUL.**

**REMEMBER, YOU ARE NOT ALONE.**