

#### YMCA RIGHT HERE

oung people promoting health and wellbeing nrough education, campaigning and influencing

## Parent and Carer Guide

A mental health support guide for parents and carers



# What will you find in this guide?

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#### INTRODUCTION



YMCA was established in 1844 and is the largest and oldest youth charity in the world, helping more than 58 million people in 119 countries. YMCA enables people to develop to their full potential in mind, body and spirit.

YMCA's Right Here project in Brighton and Hove is a youth-led award-winning project promoting the health and wellbeing of children and young people through education, campaigning and influencing.

We made this guide because we identified that there was a lack of support for parents and carers whose children had experienced mental health difficulties. This guide was designed by young volunteers aged 16-25 from the YMCA's Right Here project, but it was informed by parents and carers who gave their time to talk to us about their experiences of supporting their children through mental and emotional challenges.

You will also find quotes and tips from young people we spoke to we felt it was important we included both sides of the parent-young person relationship.

We've included a section in the middle pages of this guide, which we encourage you to give to a young person who may benefit. Many of the parents and carers we met spoke of feeling isolated, embarrassed and ashamed by the challenges they were facing. They also reported that when they had taken the step to seek professional help, they had sometimes come up against barriers in the form of not being taken seriously, being dealt with insensitively and being bounced between services.

So, this guide is a way of drawing all those experiences together, positive and negative, and helping other parents and carers who are trying to support young people.

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## Do's and don'ts!

Very little can happen without communication. These lists were compiled from numerous conversations with parents, carers and young people.

We know that a lot of this is easier said than done, especially at times when emotions or tempers are high, but if you try to be mindful of these ideas, they might just help.

### Some things to try:

- > Listen, really listen, with your full attention.
- Understand that what they're feeling is acceptable, even if it feels bad to them at that time.
- Accept your child for who they are and how they think.
   (Remember that teens think and perceive things differently to adults - and that's scientifically proven!)
- Give them opportunities to speak, but acknowledge they might not want to until they feel ready.

- Repeat back their words to show understanding. For example "Am I right in hearing that you're angry at John because he did XYZ?"
- > Give them a choice about the words you use. For example, if they have a diagnosis of bipolar, say "what do you want me to call it?"
- > Be honest with them about how you are feeling.

## ...and try to avoid:

- Patronising your child or belittling what they say.
- > Judging them, no matter what they say.
- Bombarding with questions, a two-way chat is much better.
- Using a tone (or volume) that could be perceived as aggressive.
- Reacting in a way that causes your child to shut down.
   Interrupting, at all costs: instead, give them time to say what they need to say.

Dismissing what they're feeling, for example "You shouldn't feel / say that."



## Starting a conversation

In our focus groups, we asked parents and carers about their experiences of starting conversations with their children. They gave us some interesting (and inventive) techniques. These ideas won't work for everyone but one or two might work for you and your child.

Being in a car together can help initiate conversation, but be aware that emotions can distract you from your driving, and you may have to pull over.

Try chatting over a shared, calming or creative activity like cooking, walking, decorating a room, watching a film, or something that uses your hands like drawing or painting.

Ask them to play music that expresses how they feel. Make playlists together that help them feel better or reflect their feelings.

Be active yourself (see page x) and promote activity to them, to build self-esteem and to have some common ground. Help them build on an interest they have, bearing in mind this could well be different to what they used to love. And be creative: if they like animals for example, help them find out if they could walk your neighbours' dogs or volunteer at a local animal shelter.

A light touch on their arm or shoulder can say a lot to them, or, if they react well to physical touch, give them a hug.

Try chatting online using Facebook or instant chat, even between rooms in the same house - it might be a way of communicating they're more familiar and comfortable with.

Bring out an old photo album.

#### What do young people say?

Be really aware if we are asking for help: we might not spell it out.

Respect our wishes: if we want to be left alone, please leave us alone.

Do things with us that we love to do and go to places we love to go. If you don't know what these are, ask us.

Knowing there is just someone there to talk to is reassuring.

My mum asked if I'd prefer to write it in a letter or draw it out rather than talk. This made me feel like she really cared about what I was going through, as she seemed determined to help me.

## What to say, ...and what not to say!

Communication with your child is vital, which makes the way you word things crucial so they don't feel threatened, judged, or isolated from you.

Here are some phrases that parents and carers have told us were helpful in getting their children to open up to them, and some of our own ideas too.

- > What would be helpful for you?
- > If you don't want to talk to me, let's find somebody you feel happy to chat to.
- > How can I support you?
- > What do you need me to understand?
- > What can I do to help you?
- > I'm here to listen, when you feel ready to talk.
- > I understand you're feeling [use their words here.] It must be tough for you.
  - I love you, no matter what.

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Child... I'm feeling a little depressed lately...

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Parent... How come you don't tell me anything?!

And if you don't know what to say or do, just acknowledge that out loud. Your child is likely to appreciate your honesty, and the fact that you're a human being, accepting your limits. Parent... Oh, don't be Ily, you have verything in the world going for you!

One veek later

#### What do young people say?

Whatever you do, please don't ever say "calm down", "chill out" or "cheer up."

Please don't tell us that we're "going through a phase". This isn't a phase; we need your help and support.

Try not to patronise us as we generally don't respond well to that and it could stop us from telling you how we feel in the future.

Try not to shout, or question us constantly.

Understand that mental health difficulties often go hand in hand with fatigue, and so we may not want to do the activities that we once enjoyed, or see people very often.

Be patient with us. It's daunting telling people how you really feel.

## Support for your child

We've included some pages for young people in this guide. These have lots of places your child can find support including online options, but here are some things you should know, as parents and carers, about what is out there for them.

Your child can access support / treatment around their mental health and wellbeing by speaking to their local GP.

If you are not sure where your local surgery is, you can find out by accessing the following website www.nhs.uk (UK) www.hse.ie (ROI)

Your child's GP should be able to help. Before their appointment, suggest they visit **www.docready.org** and watch the short film at *insert link* so they are prepared and know their rights.

Their GP may suggest a variety of treatment options. These could include services like CAMHS (Child Adolescent Mental Health Service), counselling / therapeutic support or medication.

It's important to discuss options with your child and support them to reach a decision about accessing the support they are happy with.

You can also find out more information on **www.findgetgive. com**, a website that has lots of different resources around mental health and wellbeing. Find Get Give has a page for parents and carers where you can access helpful resources and a blog page where you can read about other people's experiences. This website also has useful resources for young people and a page for parents and carers.

### What do young people say?

My parents offered to look into therapy with me. This helped me feel less alone and made me feel that they actively wanted to be a part of my healing process. How to get your parents or carers to communicate better with you...

These pages are from a mini-booklet written by YMCA volunteers aged 16-25 living in Brighton and Hove.

A FEW KEY TIPS:

We are trying to help parents and carers to support their children and young people more, but conversations work much better if they are two-way. We've given parents and carers loads of tips to improve their communication in the rest of the guide, but these are some ideas for you. We hope they help.

- If you want to be heard, it sounds strange but try to speak softly. Most people find it harder to hear - or listen - if you shout.
- > If you find it hard talking about how you're feeling, it could help to learn some new words insert link or build a checklist at www.findgetgive.com/vocab
- > Think about the phrases you use: we've included some suggestions on the next page.
- If talking feels too awkward right now, maybe write a letter to your parent or carer instead, or to someone who you feel could support you.

#### Here are some things we've found get a better response from our parents and carers, and seem to help them to understand us a bit better:

Instead of	Try saying
I can't be bothered	I don't have the energy
You don't understand	It feels like you're not understanding me right now
Leave me alone	I need some space
You never listen to me	Please listen to me / I need you to listen to me / This is important to me
Saying nothing	I don't want to talk right now

#### Starting 'that' conversation...

If you can regularly tick one or more of these boxes, we really suggest you talk to someone:

- A parent, carer or other relative,
- A friend, teacher, youth worker, doctor ...really it can be anyone at all!

Starting is often the hardest bit. You could try saying "I'm finding (...) really hard right now." or "Can we have a chat about (...)" or "If you've got a moment I could really do with a chat."

And check out **www.docready.org**, it was designed by young people to help prepare you to talk to your doctor, but it could be useful to start any conversation about how you're feeling.



#### Need some information or support?

- > www.findgetgive.com is a new mental health website that has lots of different resources around mental health and wellbeing for young people and parents and carers
- www.time-to-change.org.uk/youngpeople is a great no-nonsense website where you'll find loads of support (they're also at www.facebook.com/timetochange)
- www.youngminds.org.uk is a charity championing the wellbeing and mental health of young people and you'll find lots of information, advice and true stories.

For more information and support, please visit the following websites	
>	Sexual Health
	www.brook.org.uk
>	Sexuality & gender
	www.tht.org.uk/sexual-health/young-people
>	Drugs and alcohol
	www.talktofrank.com
>	Caring for someone else
	www.carers.org/about-us/about-young-carers
>	Sexual assault
	www.nhs.uk/Livewell/Sexualhealth/Pages
>	Domestic violence
	www.thehideout.org.uk
>	Bullying
	www.bullying.co.uk
>	Finding a GP
	www.nhs.uk / www.hse.ie



#### You can also talk to your doctor about your mental health, not just about physical health.

They might want to refer you to talk to someone from CAMHS (Child and Adolescent Mental Health Services) or you can ask them to refer you. You have a choice about your treatment, so ask questions.

Before your appointment, watch the film at www.findgetgive.com/howcani for your rights, and www.docready.org to help you prepare what to say.

## Support for families

There is a lot of support out there, but it can be difficult to know where to start. On these pages we list information that may be helpful and web pages that can help you find family support.

Help available can range from training to counselling to group support and much more. If you are having difficulty finding support in your area, try speaking to your GP, local council or local YMCA for some guidance.

Family Action is organisation that works to tackle some of the most complex and difficult issues facing families today – including financial hardship, mental health problems, social isolation, learning disabilities, domestic abuse, or substance misuse and alcohol problems.

#### www.family-action.org.uk

Family Lives is a charity that supports parents to deal with the changes that are a constant part of family life. This includes direct support, online forums and helplines. www.familylives.org.uk

#### **Parents tip**

It can be a good idea to clear your internet history!

Homestart is a charity organisation that offers support and friendship for families. Home-Start volunteers help families with young children deal with the challenges they face. They support parents as they learn to cope, improve their confidence and build better lives for their children. www.home-start.org.uk

YoungMinds has an excellent Parents Support Guide and provides a helpline 0808 802 5544 (Mon-Fri 9.30am-4pm) which parents and carers told us is very supportive. www.youngminds.org.uk Time To Change is a UK programme to challenge mental health stigma and discrimination, and does loads of good with young people. www.time-to-change.org.uk

Peaceful Parent includes a thoughtful, understanding newsletter you can sign up for <u>www.peacefulparent.com</u>

Ted Talks are great for inspiration. www.ted.com

#### **Recommended reading**

- Mental Health and the Resilient Therapy Toolkit (free to download!) by young people for parents: visit www.boingboing.org.uk, 'Getting hold of our stuff' and scroll down to find it
- > The Artist's Way For Parents: Raising Creative Children by Julia Cameron and Emma Lively
- Get Out of My Life But First Take Me and Alex Into Town by Tony Wolf and Suzanne Franks
- > Parenting Without Punishment by Emily Slinguff

# One mother's voice... What have I learnt from my teenage son?

"The main thing he has taught me is that as parents today, we simply cannot apply the parenting we experienced. Kids today are more informed, more savvy, they have a voice. Our job is to listen to that voice. If we don't, their voices either get louder, or disappear.

Just think...

"What can I learn here? What is my child trying to communicate to me?"

#### No matter how strong their anger or words, they are trying to communicate difficult feelings. Our job is to decipher them. And validate them. Then help them and guide them to a more peaceful inner self.

Acceptance is key: acceptance of our child exactly as they are, and of our own limits.

The lessons from my 15 year old son in the last eight months have been terrifying, bewildering and a true awakening. I thank him for that."

#### **Eating Disorders**

It can be hard to notice an eating disorder as symptoms are often quite subtle but if you have noticed a change in your child's eating or exercise habits or are even slightly concerned, you can use these services for advice:

#### > BEAT

www.b-eat.co.uk Helpline: 0808 8010677, Youthline: 0808 8010711 Email: help@b-eat.co.uk or fyp@b-eat.co.uk

> Anorexia, Bulimia Care (ABC) www.anorexiabulimiacare.org.uk Hotline 03000 11 12 13 Email:

mail@anorexiabulimiacare.org.uk

> Men Get Eating Disorders Too www.mengetedstoo.co.uk Email: sam@mengetedstoo.co.uk

#### Self-Harm

It can be really difficult for someone to open up and talk about if they are self-harming. The best thing is not to panic. You could try to find out why they self-harm (it's important to focus on the reasons and not the injuries) and listen to them. Be prepared that the young person may not understand why they self-harm, and may not be able to answer this question. Here are some reliable sites where you'll find support and advice:

- > National Self-Harm Network www.nshn.co.uk
- > LifeSIGNS www.lifesigns.org.u
- > selfharmUK www.selfharm.co.uk
- > YMCA's Right Here self-harm support guide www.findgetgive.com/selfharm
- > Royal College of Psychiatrists www.rcpsych.ac.uk/healthadvice/ parentsandyouthinfo/ parentscarers/self-harm.aspx

#### **Drugs and Alcohol**

It's not uncommon for teenagers to experiment with substances, but if you feel like your child is losing control, here are some numbers and websites to give both of you some support:

#### > FRANK

www.talktofrank.com Helpline: 0300 123 6600 Email: frank@talktofrank.com

#### > The Cool Spot

www.thecoolspot.gov

#### > Re-Solv

www.re-solv.ord

#### **Sexual Health**

Young people can feel embarrassed or shy talking about sex, but if you are comfortable, they are more likely to also feel that way and to come to you with their questions. Giving reassurance and honest answers, and signposting to places they can get support with their sexual health can help.

> Brook www.brook.org.uk

Family Planning Association www.fpa.org.uk

For urgent medical attention go with your child to A&E or call 999 / 112 for an ambulance. And keep listening to how they're feeling, without question or judgement.

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#### Suicidal Thoughts

At times, your child might experience dark or suicidal thoughts, which could be very scary for them especially if they have no one to talk to about them. As a parent or carer, you might not notice any signs that they're feeling this way - even if you do, it could be difficult to talk about, and they may not even want to talk to you about it.

If you do suspect your child is having suicidal thoughts, reading this may help you understand what they might be experiencing: www.metanoia.org/ suicide.

It's more important than ever to listen without judging or advising, and to gently reassure them you are there and that you love them. Acknowledge their feelings and signpost them to support as soon as possible.

#### > Samaritans

www.samaritans.org Helpline: 116 123 Email: jo@samaritans.org

#### > Papyrus

www.papyrus-uk.org Helpline: 0800 068 4141 Email: pat@papysrus-uk.org

#### > CALM

(Campaign Against Living Miserably) www.thecalmzone.net Helpline: 0800 58 58 58

#### Grassroots Suicide Prevention www.prevent-suicide.org.uk/ find\_help

Your family GP can help, and your child can take a friend (or you) with them if they want to. Encourage them to go urgently, and to use www.docready.org before they go. You don't need us to tell you how important it is for you to take (or make) time to look after yourself: keeping yourself emotionally strong means you'll be in a better place to support children or young people in your care.

There are some formal ways (like training courses) but the parents and carers we spoke to came up with some other ideas:

It's good

to talk!

#### Talking

Talking as openly and as often as possible to other parents, carers and friends who really understand or are in similar situations (face-to-face or on online forums - see pages x-y for ideas). This will help reduce isolation and the potential co-dependency between you and your child.

It can be hard to talk to old friends who don't understand - you may feel you have to justify your child or feel judged as a parent or carer. We all need extra help sometimes - don't be afraid to ask.

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#### **Stay active**

- Listen to music (great for releasing emotions and calming nerves)
- > Take classes or practice alone or with a friend: yoga, pilates, meditation or mindfulness... and singing!
- Go jogging, walk the dog, and dance (out or in the kitchen!)

#### **Back to basics**

- Eat healthily easier said than done, but worth a bit of thought as food really does affect mood.
- > Carry on working, if you want to.
- > Focus on one positive thing each day, however small.
- > Have a long hot soak in a bubble bath.
- Get enough sleep and allow yourself to have a lie-in.
- Reduce your own stress by giving your child a choice about their daily life (within reason) for example: "How would you like me to wake you up in the morning?"

#### Let it go

- You're only human and your child needs a human response.
   Be yourself, and no one else.
- You can't get it right all the time

   everyone makes mistakes, so
   feel your way and know your
   limits.
- It's ok to lose your temper, but if you do, just apologise: this lets your child know it's ok to make mistakes too.
- Try not to judge yourself if things don't go the way you plan them.
- Pick your battles sometimes the best thing is to walk away.
- > Don't blame your child...or your self.

Parents... "What are you gonna do with your life?!"

Child... **"I DON'T** KNOW!!'



#### **Be prepared**

- Even your family and closest friends may not understand. Excuse their ignorance, and avoid holding grudges. Accept that what some people consider as helpful ("Why don't you...?" "You should...") may sound judgemental to you. That's nobody's fault. Ask them to listen or hug you instead, and find someone who does understand there are lots of people who do.
- Learning your child's triggers can prepare you for more difficult times - and help you anticipate when those might be.
- You might come across the attitude (from professionals, friends or acquaintances) that your child's behaviour is your fault. If you're feeling like this, you are not alone. Your child's behaviour is not you responsibility.

Your child may well become angry or aggressive. It may be hard but try not to take their insults personally.

- Consider the idea of seeking counselling yourself, as your child's behaviour may trigger old traumas from your own past, and affect the way you cope with life and with your child.
- > Accept that it's likely that you may not be the best person to help your child, and your role could be more to signpost. Often parents and carers are so involved that their judgement can become clouded. You may need to find an alternative role model or someone else they can talk to.
- Respect that everyone has their own timescale for processing and recovery and there will be ups and downs. Some things take time and you might need to find new levels of patience.

## Some useful terms

There's a lot of jargon around these days. Here we help to clear up the meaning of some words you might come across in this guide, or as you go on a journey with your child.

**ADHD (ADD):** Attention Deficit Hyperactivity Disorder includes behavioural symptoms that include hyperactivity and impulsiveness.

Anorexia: an eating disorder characterised by immoderate food restriction and irrational fear of gaining weight, as well as a distorted body self-perception.

#### Anxiety disorders: range from

feelings of uneasiness to immobilising bouts of terror, including panic attacks. If a person cannot shake their worries, or if the feelings are affecting their everyday activities, talking to someone would be the first step. **Bipolar disorder:** aka manic depression, often with extreme mood swings with recurrent episodes of depression and mania (being high or up).

**BME:** Black and Minority Ethnic.

**CAMHS:** Child and Adolescent Mental Health Services.

**CBT:** Cognitive Behaviour Therapy, a talking therapy that can help someone manage difficulties by altering the way they think and therefore behave.

**Counsellor:** someone who provides advice and support to another person or persons



**Depression:** a mood disorder characterised by intense feelings of sadness that persist beyond a few weeks. It is associated with many physical symptoms such as disturbance of sleep, appetite, and concentration. Often associated with anxiety.

**CPN:** Community Practice Nurse.

**Dual diagnosis:** a term used to describe patients with both mental health difficulties and substance misuse.

**EMDR:** Eye Movement Desensitization and Reprocessing, a therapy to try and reduce your reaction to memories and triggers, often related to a traumatic event.

Healthwatch: the best way to give your feedback about any health service you have received: www.healthwatch.co.uk **LGBTU:** Lesbian, Gay, Bisexual, Transgender and Unsure.

**OCD:** Obsessive Compulsive Disorder, which can cause severe anxiety in those affected.

**Panic attack:** a period of intense fear or apprehension that can happen suddenly and last minutes or hours.

Personality disorders: a group of conditions characterised by an inability to get on with other people and learn from experience. People with a personality disorder may find that their beliefs and attitudes are different from those of most other people. Others may find their behaviour unusual, unexpected or perhaps offensive.

**Primary care:** health service provided by your GP (General Practitioner).

**Psychiatrist:** someone who diagnoses mental health difficulties and prescribes medication.

**Psychologist:** someone who deals with the way the mind works and helps people to cope more effectively with their mental health difficulties.

**Psychosis:** a mental health difficulty that may stop a person from telling the difference between reality and their imagination.

**PTSD:** Post Traumatic Stress Disorder, a type of anxiety caused by stressful, frightening or distressing event.

**Resilience:** the ability to recover quickly from difficulties or problems.

Schizophrenia: a disorder that can make people experience things that may not be real, there's many different types of schizophrenia and one person's may be different from others. **Self-harm:** a way in which someone might cope with or express distress or choose to communicate. There are many different forms, for example scratching, cutting or hitting.

**Suicidal thoughts:** a thought about ending your own life, possibly including making plans.

**Secondary care:** medical care provided by a specialist or facility, usually through a referral from a GP.

**Stigma:** judging something negatively before you fully understand it.

Wellbeing: someone's mental state, how they feel and how well they can cope day to day. Our wellbeing can change from day to day, month to month or year to year.

## Thank you

It wouldn't have been possible to create this guide without the help of the parents and carers and young people who shared their experiences at our focus groups or on our online surveys, and the professionals who offered their expertise. Special thank yous to **Rachelle Howard** and **Sophie Larsen** for their time and thoughtful insight and to **Kelly Bastow** (aka moosekleenex.tumblr.com) for allowing us to use extracts from her perceptive cartoons. In this YMCA guide you'll find real-life experiences of parents and carers who have supported their children with mental and emotional challenges. You'll also see what young people have to say about the support they've received (or not) from their parents carers.

If you are worried about your child or a young person you know, picking up this guide could be the first step to opening up one of the most important conversations of their lives.

To contact us with any comments or updates, or if you would like to order printed or localised versions of this guide, please contact: cat.pritchard@ymcadlg.org



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YMCA enables people to develop their full potential in mind, body and spirit. Inspired by, and faithful to, our Christian values, we create supportive, inclusive and energising communities, where young people can truly belong, contribute and thrive.

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