

Crisis Prevention



A Family Survival Guide

Created by Families



LOTTERY FUNDED

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Foreword

I am really pleased to have been asked to provide this foreword. I have had the privilege to attend the Bringing Us Together group and to listen to the stories of children and their families. Children and Families who have been put in impossible circumstances, which are distressing and desperate, and have still found a way to support each other, and to make the state, rightly sit up and listen. Much of the impetus on the work on people and, specifically children, with autism and learning disabilities, which is now reflected in the NHS 10 year plan has come from the group and from parents and young people who have experienced the system.

This guide, reflects the groups approach, it puts families and young people at the heart and is written intelligently and empathetically for families who are in a challenging place.

It is person centred and practical and full of helpful tips and strategies. I really admire the way it starts with children and young people but also explains the system and how to make the best of it.

While it is written by and for families, it will also be incredibly useful for professionals to understand the way the system works and impacts, and that at the heart of it are human beings .

I am very happy to support the guide and to promote it, I want all families who need it to know about it, and the professional who work with them to understand it.

Dame Christine Lenehan

Director
Council for Disabled Children

Introduction

This guide has been written by families for families of children and adults with learning disabilities, autism or both. It has been a difficult guide to write given the massive challenges that the Health, Education and Social care systems are currently facing. Many families, who are caring for loved ones living with learning disabilities, autism or both and whose behaviour is seen as challenging, continue to find it difficult to obtain ongoing appropriate care and support.

Bringing Us Together is a small and proactive organisation with a wide network of families. We believe in doing what we can to help change the system, and to correct the frequent failings and shortcomings that often lead to families ending up in crisis. In this guide, we hope to give you the information you need to understand how the system works. We also try to signpost to people who can provide help and advice, so you will be better equipped to get your loved one's needs appropriately assessed and met.

What is a crisis?

A crisis is any situation in which you feel you – or your loved one – need help urgently. There is no single definition of a crisis as it depends on each individual situation and the perceptions and reactions of those affected. Caring for someone living with a learning disability, autism or both whose behaviour is seen as challenging can bring additional physical and emotional challenges (and sometimes risk), which can escalate very quickly.

In general terms, a crisis can mean feeling unable to cope with your situation or keep yourself or those around you safe. You – or your loved one – may also feel great emotional distress or anxiety.

Urgent Help

If you are reading this, it is likely that your routine is challenging on a daily basis. However, if you are worried about the immediate safety of your loved one, and they are at risk of hurting themselves or others around them, it is important for you to take one of the following actions (depending upon your circumstances).

- If you have already been given a Crisis Line number from a health professional, ring it straightaway.
- If your loved one is under the care of a mental health team and has a specific Care Plan that states who to contact when they need urgent care, follow this plan.
- If your loved one is under the care of a mental health team and has a specific Care Plan that states who to contact when they need urgent care, follow this plan.
- If urgent, but not life-threatening, book an emergency appointment with your GP or call 111 for advice.
- If there is an acute and immediate threat to life, go to your nearest Accident and Emergency department (A&E) if you can get there safely. If not, call 999 and ask for police and ambulance response.

NB: This advice has been taken from NHSE guidance available at: <https://www.nhs.uk/using-the-nhs/nhs-services/mental-health-services/dealing-with-a-mental-health-crisis-or-emergency/>

Why is this guide needed?

Through our work with families over several years, we know that far too many families end up in crisis, sometimes resulting in their loved ones spending very long periods in mental health hospital Assessment and Treatment Units (ATUs).

Assessment and Treatment Units (ATU) – is a type of hospital inpatient unit designed to provide hopefully short-term secure placements for people with learning disabilities who have been admitted following a crisis in the community.

About Us

Bringing Us Together is led by parents of children and young people with a variety of Special Educational Needs and Disabilities (SEND). We bring families together to share experiences, stories and solutions so they can create a life worth living for their loved ones. Find out more at <https://bringingusttogether.org.uk>

Why do people with learning disabilities, autism or both end up in ATUs?

In June 2016, Bringing Us Together ran an event for parents who had experienced a crisis that had resulted in their loved ones being admitted to hospital ATUs. You can find out more about the event here:

<http://bringingusttogether.org.uk/wp-content/uploads/2016/07/Stronger-Together-June-2016.pdf>

The main challenges

During the event, we asked families about the main challenges they experienced with the system. The following themes emerged:

- Social Care and local services;
- SEN Issues;
- personalisation;
- legal support and information;
- parents seen as the problem;
- fuller (non-medicalised) understanding of learning disability and autism;
- concern over use of the Police and the Criminal Justice System;
- mental health and emotional well-being;
- the complaints system;

- Care and Treatment Reviews (CTRs);
- over-medication;
- staffing in Assessment Treatment Units (ATUs); and
- The discharge experience.

Avoiding Crisis – Support Needed

Following our parents' event in July 2016, Bringing Us Together and a charity called Respond undertook a piece of work with families called *Avoiding Crisis – A Parent Survey on Support Needed*. You can read the report here:

<http://bringingustogether.org.uk/wp-content/uploads/2016/07/Justice-Together-Support-Needed-15.07.16-CK-v2-3.pdf>

The *Avoiding Crisis* project aimed to find out about the experiences of families and particularly the support they received in crisis. We had 86 responses from 53 different Local Authority areas across England. The results were then collated and a report produced. Some of the responses from the survey were shocking. Here are some of the key findings.

- Only just over half of the families reported being given any advice on where to seek help.
- Even when advice and guidance was given, families often found that help was hard to get and inadequate. Some families were too exhausted by the caring role to follow it up.
- Telephone help lines were generally not felt to be useful, while internet access, discussion groups and support from other parents were felt to be more helpful.
- When families actually found and accessed support, there was a 50/50 split between those who found the support package helpful and those for whom it was not helpful.
- Families identified emotional support, specialist advice, circles of support, advocacy and legal advice as the top priorities to sustain and support them.
- 52% of those experiencing a crisis had a relative with autism.

- 71% of families who had a relative with Down Syndrome had experienced crisis.
- 83% of families caring for a relative with mental health needs recorded that they were unable to cope.

This anecdotal evidence made it clear to us that families need more advice support and information. This guide is one of the ways we have tried to help.

How to use this guide

This information aims to support families to understand and access their local education, health and care services, and to avoid a potential crisis. We've included tools, references and links to further resources, so that you can dip in and out as required.

Please tell your friends and colleagues about this guide. All feedback – good or bad - is very welcome. We want to make this guide as useful as possible. Contact us at: **Debs@bringingustgether.org.uk**

Living with behaviour that challenges

What is Challenging Behaviour?

As set out on page 14 of *Challenging Behaviour: A Unified Approach*, Royal College of Psychiatrists *et al* (2007), challenging behaviour is defined as behaviour 'of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others, and is likely to lead to responses that are restrictive, aversive or result in exclusion.' You can find the full reference at: <https://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr144.aspx>.

Examples of challenging behaviour include: hitting, kicking, spitting, throwing things, self-harming, self-injury, biting, scratching, trichotillomania (pulling hair out), damaging the environment or clothing, screaming, pica (eating non-food items) and smearing.

You can find more information on challenging behaviour at: <https://www.challengingbehaviour.org.uk/about-us/what-is-c-b/what-is-challenging-behaviour.html>.

Please note: The term 'challenging behaviour' here is not intended as a diagnosis or label used to describe people who display it, but rather to describe the effect of the behaviour on those around the person, as it is them who are 'challenged' by the behaviour.

Causes of challenging behaviour

The root causes of challenging behaviour can be physical, emotional or social, and will likely be the result of an unmet need. All behaviour is a form of communication, and all behaviour has a reason and/or purpose. For those living with a learning disability, autism or both, difficulties in understanding and using language can make it difficult to communicate needs effectively (e.g. hunger, thirst, discomfort or pain). It is likely that they have learned over time that, as their behaviour often gets an instant reaction, it is a useful communication technique to use to get noticed and gain some control over their situation.

Challenging behaviour can be caused by any number of things for what may seem to us the smallest of reasons, but for the person may be very hard for some to cope with, for example:

- **changes in routine or to the environment** (even something that may seem very subtle to others);
- **sensory issues**, which can be particularly overloading for people with autism because of sensory processing differences (e.g. pain, distress caused by loud noise, the light touch of clothes labels in clothes);
- **differences in understanding and getting on with others** (i.e. the social communication difficulties diagnosed in autism) and **differences in thinking flexibly** (e.g. social imagination difficulties characteristic of autism);
- **sensitivity to the moods of people** around them, difficulties trying to communicate health needs (hunger, thirst, pain or discomfort; and
- **significant life changes or transitions** concerning family or home life (e.g. puberty, transition to adult services, death of a loved one or moving home).

The consequent increase in anxiety, confusion or discomfort can result in challenging behaviour that requires others to identify then reduce or remove the cause(s) of the distress.

While some behaviour may be seen regularly, a sudden change could indicate something serious, such as an undiagnosed health problem in

need of some timely attention. Although it could just be a minor tummy upset or a developing cold, it could also indicate more significant or fluctuating pain and infection (e.g. earache, toothache, constipation) or even something more serious. If there is any doubt, call your GP. Other examples of health-related issues that can impact upon behaviour include: epilepsy, vision and hearing impairments, the side effects of medication, allergies, and mental health illness.

Please note: There is a wealth of evidence that people with learning disabilities often have unmet health needs, so it is always recommended to think health first when a person is showing behaviours or distress.

What causes a crisis?

Many families who care for loved ones with complex and sometimes challenging needs can find things tough at the best of times. It does not take much for things to start falling apart if families are not getting the advice and support they need, or if there is a sudden upsurge in behaviour for whatever reason. Caring for someone with high needs can also be exhausting and affect mood and wellbeing, which can result in your own health being affected. We hear from many families who suffer from anxiety, depression and lack of sleep. You can see our report on Parent Carer health at <http://bringingustogether.org.uk/wp-content/uploads/2018/05/Parent-Carer-Health-final.pdf>

Whatever the reason for challenging behaviour, it is vital for the individual, and those around them, that their needs are understood and addressed. All behaviour has a function and a trigger. Careful analysis can often reveal what is going on to better understand what the person is trying to tell us and then use what we learn to modify our approach to make a difference. It is not just about being right or wrong.

Assessment and support

The most important aim is to improve the quality of life of the person whose behaviour may be challenging others. To help achieve this, an approach called Positive Behaviour Support (PBS) can be used to undertake a comprehensive review of the behaviour. The review will look at what the function of the behaviour is, what it is communicating and how to make adjustments or teach skills the person might need to help them manage the challenge they are facing. This is recorded in their person's PBS Plan, which can then be used by carers and supporters to better meet the needs of the person on a daily basis to prevent or reduce challenging behaviours.

The PBS review will also look at health, psychological or psychiatric factors, communication, social or environmental issues to gain knowledge and insight about the person's background, and support needs. As already mentioned, a sudden change in behaviour could indicate a significant health issue, so your loved one's GP should be one of the first involved. Health needs must be properly assessed and managed.

It is important for you to share any information you have for your loved one (e.g. a medical history, diagnoses, developmental and emotional difficulties, language development and any sensory challenges), with consent if needed. Your GP can assist if you need advice and may offer to refer you to the local Community Learning Disability Team (CLDT). If you haven't got them on speed dial already!

You may have support documents, such as a Communication Passport, details of medication, a health action plan, nursing assessments, occupational therapy and speech and language reports. These are useful in reviewing your loved one's personal profile and background, in order to rule out all health or physical causes for the behaviour. Your GP or the CLDT can help you obtain and/or develop these.

A clinical psychologist or behaviour specialist may be asked to conduct an in-depth review using the information provided and by talking to those who know the person the best. They will then undertake a detailed

functional assessment of behaviour, considering underlying medical and organic factors, psychological/ psychiatric factors, communication and social/environmental factors, which should lead to a clear understanding of the behaviours of concern. A PBS Plan is then produced, which identifies each behaviour and states the proactive and reactive strategies necessary to understand and reduce the specific behaviour. The aim is to develop alternative ways of meeting needs to avoid the person resorting to challenging behaviour.

All strategies should be based upon the least restrictive principles in relation to managing risk. Regular reviews, good communication and sharing of information between professionals, your loved one and their family are vital to make the PBS plan work effectively.

Please note: Never forget, you cannot do it all by yourself! As a carer, you are entitled to an assessment of your needs too. If you are overtired and struggling, your behaviour can influence your loved one's behaviour too. However, do not forget that this is because of your unmet needs and it is not your fault! We all can feel guilty and blame ourselves at times.

Further Information

[Challenging behaviour: a unified approach](#) – updated Clinical and service guidelines for supporting children, young people and adults with intellectual disabilities who are at risk of receiving abusive or restrictive practices

<https://www.bps.org.uk/files/challenging-behaviour-unified-approach-updatepdf>

[Challenging Behaviour - the basics](#) from the Challenging Behaviour Foundation:

<http://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/cb-the-basics.html>

An Introduction to Positive Behaviours

<https://m.youtube.com/watch?v=epjud2Of610>

Positive Behaviour Support Resources factsheets from PBS4

<https://pbs4.org.uk/resources-factsheets/>

Positive Behaviour Support Resources from the PBS Academy

<http://pbsacademy.org.uk/family-carers/>

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges

<https://www.nice.org.uk/guidance/ng11>

Assessing behaviour that challenges

<https://www.nice.org.uk/guidance/ng11/ifp/chapter/assessing-behaviour-that-challenges>

Behaviours that challenge: Ambitious about Autism

<https://www.ambitiousaboutautism.org.uk/understanding-autism/behaviour/behaviours-that-challenge>

Behaviour

<https://www.scope.org.uk/support/tips/behaviour/challenging-behaviour>

Physical challenging behaviour National Autistic Society

<https://www.autism.org.uk/about/behaviour/challenging-behaviour/physical.aspx>

Life stage trigger points and how to mitigate these

Any young person may experience a number of significant and one or two traumatic transitions as they grow (e.g. moving house, a parent leaving or the death of a family member). However, two of the biggest, most predictable trigger points in the life of someone with a learning disability, autism or both are puberty and their transition to adulthood.

Puberty

Puberty can prove difficult for many young people given the hormonal, emotional and physical changes taking place. Sexual development and hormonal changes (e.g. erections, menstruation, mood swings) can cause increases in anxiety, aggression, low self-esteem and depression.

For those with a learning disability, autism or both, these new sensations and feelings can be very difficult to adjust to, especially for those with more complex needs. The result can be very confusing for the young person and even frightening as they may not have the skills required to understand or communicate feelings to parents and/or peers.

Every young person is different but, if it is appropriate, starting conversations early can be really helpful. Talking about the body, naming all the parts and what all the bits do in basic terms, will reduce embarrassment later on and make conversations so much easier.

When the time comes, your child's school should start the dialogue formally as a part of the PHSE curriculum, but by using picture books and other resources early on your child (and you) should find it easier to understand. Some links to resources can be found below and there are also some low-cost materials available from a number of sources, including Amazon.

You can also ask for help from your child's school, GP or contact a local support group. You can find details of local support groups at <https://www.contact.org.uk/advice-and-support/parent-support-groups/find-a-local-support-group/>

Further Information

Puberty and growing up

<https://contact.org.uk/advice-and-support/your-child-your-family/growing-up-sex-and-relationships/puberty-and-growing-up/>

Growing up, sex and relationships: A guide to support parents of young disabled people

https://contact.org.uk/media/1160021/growing_up_parents.pdf

10 Tips to Support Children with Autism through Puberty, Adolescence and Beyond

<http://www.jkp.com/jkpblog/wp-content/uploads/2014/04/10-Tips-Autism-Puberty-Adolescence.pdf>

Puberty and Growing Up (2010)

https://www.lincspcf.org.uk/DocsLibrary/LPCC_Puberty_Report_2010_10.pdf

Sex education and puberty

<https://www.autism.org.uk/about/communication/sex-education.aspx>

Let's talk about puberty

http://www.easyhealth.org.uk/sites/default/files/Lets_Talk_About_Puberty.pdf

Growing up – What’s it all about?

<https://www.nhs.uk/Livewell/puberty/Documents/4youmarch2010nonprinting.pdf>

Transition to adulthood

The purpose of transition planning is to help prepare a young person for their future in adult life. Achieving a successful transition to adulthood takes very careful planning, with everyone working together and planning being driven by the young person’s needs, abilities and desires. Focussing upon their education, health and care needs in one combined Education and Health Care Plan (EHCP) will help your loved one build skills to learn, live, work and enjoy life in their communities and beyond.

For young people with disabilities, future options could include:

- leaving school
- going to college or university
- getting a job
- living happily with my family at home and having all my needs met
- getting support from Health and Adult Services to stay healthy and happy
- moving in to independent living / supported living
- becoming a world-renowned scientist, a famous writer or musician, and/or
- doing anything you want to do and being anyone you want to be!

Focussing on what a person can do, rather than what they cannot do, will help them fulfil their potential and ultimately improve their quality of life. It is important to make sure that their personal health and care needs are fully met in order to minimise the risks of avoidable difficulties or crisis situations occurring.

Any transition in life can pose challenges. Moving on to the adult world is a big step that can be both exciting and traumatic for young people and families alike. Reaching adulthood can bring huge changes, as the responsibility for care and support now passes from Children and Young People’s services to Adult Services, which use different laws, rules,

policies and procedures so being prepared is vital. If transition planning is done successfully, it can help the person flourish.

With age also comes a change in decision-making and responsibility. As the young adult approaches the age of 18, they have a right to start make their own decisions (assuming they have the mental capacity to do so). However, subject to your loved one's agreement, you will still be able to give advice and be there to provide support.

Please note: If mental capacity is ever uncertain, a mental capacity assessment and best interest principles will be used to inform and enact decision-making appropriately.

Planning for transition to adulthood should start when the young person reaches the age of 14. If your loved one has been assessed as needing more help than is available through special educational needs (SEN) support they will be eligible for an EHCP. The EHCP is key to developing and maintaining the right support so that all needs can be identified and met effectively.

Find out more about EHCPs here:

Education, Health and Care Plans: Examples of good practice (CDC)

<https://councilfordisabledchildren.org.uk/help-resources/resources/education-health-and-care-plans-examples-good-practice>

There is no 'one-size-fits-all' approach to transition. Attention to detail is very important, both to meet current needs, and to develop a clear approach for the future.

Supporting Transition

Here are some of the ways in which you can support your child through Transition to adult services.

- **Focus on the person**

- Listen to their voice always.
- Meaningfully involve the young person as much as possible.
- Encourage the young person to speak up to get what they need.

- **Quality of life**

- Identify clear goals and aspirations.
- Person-centred planning must always be developed to enable your loved one to have a happy, healthy and fulfilled life.
- Develop and promote independence.
- Ensure that care and support meets the person's needs, always!

- **Preparation**

- Research the EHCP process (e.g. use the resources below).
- Be prepared for meetings beforehand and know what you want to ask.
- Have the people present who you would like there.
- Take advantage of any related training on offer that you may find helpful.

- **Planning & Reviews**

- Get involved in the planning process to ensure that it is meaningful and truly person-centred.
- Get involved in reviews at school.

- **Working together**

- Maintain respectful relationships with others involved in the process.
- Make sure information is shared with the people who need to know to ensure that different services and agencies are working together.
- Ask questions if anything is not clear or if you have any concerns.

- **Information**

- Assemble essential documentation (e.g. a Pen Picture/One Page Profile, Communication Passport, Care Plan, Health Action Plan).
- Make sure you have all the necessary information and detailed reports in order to help make choices and decisions.
- Be an active member of your local parent carer organisation in order to receive information about the different kinds of support offered to parents and carers. It will also give you an opportunity for your voice to be heard, to influence decisions and make a difference.

- **Record-Keeping**

- Build and maintain records of diagnoses as evidence will be vital.
- Include details of assessments and professional's reports which highlight specific needs and benefits if appropriate.
- Keep a record of all your meetings and decisions made.

- **Progress**

- Make sure you know what actions have been taken or agreed.
- Keep thinking about what is in the EHCP and make sure that it is flexible.

- **Options**

- Make sure you go and look at different options and opportunities as they emerge, ask questions and make notes afterwards.

Further Information

Education, Child Social Care and Transition (Challenging Behaviour Foundation)

<https://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/educationandtransition.html>

Transition: National Association of Special Educational Needs (NASEN)

<http://www.nasen.org.uk/resources/resources.transition.html>

Preparing for Adulthood

<https://www.preparingforadulthood.org.uk/>

Building independence through planning for transition: A quick guide for practitioners supporting young people Preparing for Adulthood

<https://www.preparingforadulthood.org.uk/SiteAssets/Downloads/x3qxy1xr636379670314536294.pdf>

Factsheet: Transition to Adulthood in England for parents/carers of children with a learning disability Cerebra

<https://www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-transition-to-adulthood-in-england-for-parents-carers-of-children-with-a-learning-disability/>

Transition Scope

<https://www.scope.org.uk/transition>

The Council for Disabled Children

<https://councilfordisabledchildren.org.uk/>

Moving into Adulthood and Getting a Life Oxfordshire family support network

<https://www.oxfsn.org.uk/moving-into-adulthood/getting-a-life-guides/>

Transition Pathway Diagram (Oxfordshire family support network)
<https://www2.oxfordshire.gov.uk/cms/sites/default/files/folders/documents/childreducationandfamilies/educationandlearning/specialeducationalneeds/supportforparents/Movingintoadulthood.pdf>

14 – 25 Transitions Guide Sheffield PCF
https://sheffieldparentcarerforum.org.uk/wp-content/uploads/2016/04/Transition-Timeline_web.pdf

Legislation topics

Special Educational Needs and Disability Code of Practice: 0 to 25 years

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

The Care Act: Transition from Childhood to Adulthood (SCIE)

<https://www.scie.org.uk/care-act-2014/transition-from-childhood-to-adulthood/>

National Institute for Health and Care Excellence (NICE) Publications

Transition from children's to adults' services for young people using health or social care services: NICE guideline [NG43]

Published date: February 2016

<https://www.nice.org.uk/guidance/ng43>

Transition from children's to adults' services: Quality standard [QS140] Dec. 2016

<https://www.nice.org.uk/guidance/qs140>

Getting the right Education Health and Care Plan

An Education, Health and Care Plan (EHCP) is for children and young people aged up to 25 who need more educational support than is available through special educational needs (SEN) support. An EHCP sets out the education, health and social care needs your child or young person has and the support that is necessary to cater for those needs. It is important that your loved one's needs and the provision they require is described accurately and located in the correct Section of the Plan. If you are concerned that this is not the case, or if you think your loved one's needs may have changed, you can ask for an emergency review. You can find out more about EHCPs below.

Further Information

Education, Health and Care plans IPSEA

<https://www.ipsea.org.uk/Pages/Category/education-health-and-care-plans>

Education, Health and Care (EHC) plans Contact

[https://contact.org.uk/advice-and-support/education-learning/education-health-and-care-\(ehc\)-plans/](https://contact.org.uk/advice-and-support/education-learning/education-health-and-care-(ehc)-plans/)

Education, health and care plans in England NAS

<https://www.autism.org.uk/about/in-education/extra-help-in-school/england/ehc-plans.aspx>

Special educational needs and disability A guide for parents and carers August 2014

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/417435/

[Special_educational_needs_and_disabilites_guide_for_parents_and_carers.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/417435/Special_educational_needs_and_disabilites_guide_for_parents_and_carers.pdf)

EHCPs good practice examples CDC

<https://councilfordisabledchildren.org.uk/help-resources/resources/education-health-and-care-plans-examples-good-practice>

Keeping your loved one and others safe

We have already covered the potential causes of behaviour that challenges, including the use of strategies such as Positive Behaviour Support (PBS) and developing a behaviour support plan. A good behaviour support plan sets out possible triggers and provides alternative ways of meeting needs to avoid the person resorting to challenging behaviour. All strategies should be based upon the least restrictive principles in relation to managing risk. It is also important to remember that a sudden change in behaviour could be due to a health issue and to therefore contact the GP straightaway.

A PBS plan can help those working with your loved one to cope with any known behaviour and adapt accordingly in order to best meet the person's needs. However, given the unique needs and sensitivities of each individual, there is always the possibility of a sudden and unexpected escalation of behaviour.

Staying safe at home

Although you know your loved one better than anyone else, the potential for unexpected behaviour is still something to be wary of. The smallest of things can trigger a sudden escalation in behaviour, which might risk harm to the person themselves or those around them. It is important to manage the potential risks, the dangers to/from the environment and, as far as possible, defuse any escalation of behaviour. Using a calm and understanding approach, and offering your loved one reassurance, one or two incentives and choices, is usually helpful.

Before outlining our suggested approach, it is important to recognise something else that can prove difficult to manage - our own expectations! We are mum or dad and they are our son or daughter. We have our own perceptions and values as to what constitutes good, bad or acceptable

behaviour that have developed as we have grown up. Making allowances when your child has a learning disability or autism can therefore sometimes not be the first thing you think of when experiencing sudden and unexpected challenging behaviour. Your immediate reaction, if defensive or perceived to be aggressive, could make the situation even worse. It is therefore important to try to stay calm and remember that the behaviour is a cry for help.

Physical Intervention

Please note: Physical interventions should always be a last resort. It should only be done if you really know what you're doing. Unless you have proper training and/or if the person is in immediate and significant danger, you should stick to non-restrictive methods as much as you can.

De-escalation strategies - you can do this!

Please note: None of the following information regarding de-escalation and staying safe constitutes official or professional advice. It is general information offered by parents who are providing suggestions based upon their own lived experience. If you require specialist intervention advice, please contact your loved one's care manager or a behaviour specialist. We also recommend seeking professional guidance for any behaviour that carries a risk of actual or potential self-harm. Do not be afraid to ask for help from professionals - there are lots of advantages to being able to work together to find out the causes for behaviour.

Every person and every situation is unique. It is important for any strategy you use to be in accordance with any current behaviour management plan. However, we have suggested some generic interventions below to help you calm the person and assist recovery.

It is also important to recognise that you know your loved one best. Trust your instincts as to what works best for them. You are the expert in your own child. Share your knowledge with carers working with your loved one in a non-confrontational way.

Please note: Always keep a list of emergency contacts close at hand just in case and store all the numbers in your phone too for instant access.

Top de-escalation tips suggested by families

- Send others away from the immediate area and ask them to keep out of sight.
- Remove dangerous objects and keep the person as safe as you can.
- Try to remain in control and stay calm. Say as little as possible. Use a calm voice and avoid disciplining.
- Disengage emotionally, and try not to take the behaviour personally.
- Avoid standing face-to-face. Instead, turn to one side to remain non-threatening.
- Present yourself as a helper rather than an enforcer.
- Try redirection (e.g. offer two acceptable choices to give them a sense of control).
- Offer incentives to try and help them think past the immediate situation.
- Back away if danger or if you are being targeted. Turn your back or temporarily go into the next room. Stay out of range but still within reach but only do this if safe to do so.

Helpful suggestions to minimise distress

- Always be risk alert. History is the best predictor of the future. If, for example, you know that your loved one can pull your hair when they are stood behind you, be alert to this risk and their movements.
- Be aware of where your exits are, and if you are feeling in danger, consider if leaving the room is the safest option.

- Remain calm. Emotions can run high in difficult situations, so try not to let your emotions control your actions. Although the behaviour is directed at you, it is likely that your son/daughter feels safest expressing themselves with you and it is therefore unlikely to be personal or your fault.
- Try active listening. Get on their level, mirror their body language and match their mood. They will see you are then 'on their side' rather than someone to challenge. Once you have engaged and matched their mood, you can try slowing down your communication and the volume of your voice. It is likely your son/daughter will mirror you.
- Humour is great at diffusing situations. Try doing something silly to make them laugh. Laughing is often incompatible with anger.
- Can you make some drastic change that will make them pause and wonder what is going on? This might be putting on their favourite song on full blast, bursting into song, changing the colour of the lightbulbs in a room, coming in with a silly wig or mask on.
- Try a change of scenery, together or alone. Sometimes being in a different place can relieve the tension.
- Think about how you can make the room feel more spacious. Ask other people to move out of the area, remove things that could cause harm, open doors and windows.
- Reduce verbal communication. Many people with learning disabilities, autism or both struggle to understand verbal communication. The ability to do this is further reduced when they are distressed or agitated.
- Can you give them what they want? Sometimes it is easy to get caught in a battle of trying to win, but sometimes 'letting them win' is ok.
- Try to make highly preferred items available as a competing option. They could carry on with the risk of being physically challenging towards you, or they could go into the kitchen where there is lovely apple pie and ice cream!
- Use interests and fixations. For example, if they are obsessed with watching their favourite TV programme, put it on or try to introduce a favourite toy, item or activity. If they become absorbed in that they will be less likely to show physical challenge to you.

- Consider physical contact. Sometimes a hug, or a reassuring touch can be what is needed, and they may not understand their actions are making you move away.
- Try to avoid demanding an apology. We all find it difficult to say sorry, so why should your son/daughter find it easy? They may not understand the apology or know how to repair relationships when things go wrong. But if they want to say sorry, by all means welcome it with open arms.
- Try to forgive and forget quickly, and avoid bearing grudges. They say every day is a new day, well sometimes it has to be every minute is a new minute!
- Remember to take care of your own emotional wellbeing. See here for some helpful information <https://www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-emotional-well/>.

Requesting help in an emergency

If you are worried about the immediate safety of your loved one, or they are at risk of hurting themselves or others around them, take one of the following actions depending upon your circumstances:

- If you have already been given a Crisis Line number from a health professional, ring them straightaway.
- If your loved one has a care plan that states who to contact when you need urgent care, follow this plan.
- If it is an emergency, call 999 and ask for a police and ambulance response if the person's behaviour presents a serious risk to themselves and / or others.

For further information about when to call 999 go to: <https://www.nhs.uk/using-the-nhs/nhs-services/urgent-and-emergency-care/when-to-call-999/>

Overview of the Assessment and Review System

This section aims to explain what the current local and a national care and treatment system looks like in the context of this guide.

The NHS England Transforming Care programme was developed to help improve health and care services so that more people with learning disabilities, autism or both who have a mental illness or whose behaviour challenges services can live in their own communities, with the right support and close to home. This would mean that fewer people need to go into hospital for their care.

Care and Treatment Reviews

The programme consists of a number of work streams. One of these, called Care and Treatment Reviews (CTRs), focuses on three things:

- reducing the number of people reaching crisis in their community and ending up in hospital for assessment and treatment;
- making sure that care meets the person's needs fully if in hospital; and
- trying to reduce the length of inpatient stays by focussing on current and future care planning, including plans for leaving hospital.

A CTR is carried out at pre-defined periods (see below) by an independent panel of expert reviewers and can be held in hospital or in the community.

For Children and Young people, it is called a Care, Education and Treatment Review (CETR), to make sure that their education needs are considered alongside health and care. Detailed National Policy and guidance governs the whole process to make sure that reviews are carried out to a consistent high standard.

CTRs and CETRs seek to answer four questions from the perspective of the patient.

- Am I safe?
- What is my current care like?
- Is there a plan in place for my future?
- Do I need to be in hospital for my care and treatment?

Most importantly, the patient and their family (with the patient's consent, if required) can also take part in the review and have their voices heard.

CTRs are held as follows:

- prior to admission, as required;
- post-admission (within four weeks of admission or within two weeks for children and young people);
- every six months for adults in non-secure hospitals;
- every 12 months for adults in secure hospitals; and
- every three months for children and young people in hospital.

Community CTRs

The aim of a community CTR is to prevent a hospital admission where it is being actively considered or sought because of an impending crisis in the community.

The CTR panel will include the views of all those involved in supporting the individual in order to prevent an inappropriate hospital admission. It will look at your loved one's needs and the care they require. The panel can then establish whether they need to be admitted to hospital or whether their care and treatment needs could continue to be met effectively and safely in the community through additional and/or alternative support and interventions.

Inpatient CTRs

Inpatient reviews held at regular intervals will comprise a panel consisting of the responsible commissioner, representatives of the care team including the ward manager, psychiatrist and therapists.

Other health and social care professionals and strategic commissioners will be invited to attend as required. Independent members of the panel will consist of a clinical expert and someone with lived experience of learning disabilities, autism or both. The agenda will allow for detailed assessment of the needs of the patient, current care and discharge planning.

For children and young people, the CETR should also include appropriate representation from children's services to enable the educational needs of the child or young person to be discussed and addressed.

You can find out more about CTRs by reading Bringing Us Together's CTR family Survival Guide at: <https://www.ndti.org.uk/uploads/files/CTR-Survival-Guide-Aug-2017-1.pdf>

Further Information

Care and Treatment Reviews: Policy and Guidance

<https://www.england.nhs.uk/wp-content/uploads/2017/03/ctr-policy-v2.pdf>

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition:

Service model for commissioners of health and social care services

<https://www.england.nhs.uk/publication/service-model-for-commissioners-supporting-people-with-a-learning-disability-and-or-autism-who-display-behaviour-that-challenges-including-those-with-a-mental-health-condition/>

Transforming Care for People with Learning Disabilities – Next Steps

<https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf>

Care and Treatment Reviews homepage

<https://www.england.nhs.uk/learning-disabilities/care/ctr/>

CTR/CETR Code and toolkit

<https://www.england.nhs.uk/publication/care-and-treatment-review-code-and-toolkit/>

How do local health and care services know who needs urgent help?

Local monitoring and intervention should take account of the following:

- Is the person placing themselves or others at serious and/or significant risk of harm?
- Is the person's community placement or tenancy at risk of irretrievable breakdown and does this pose a significant risk to the safety of the person and/or others?
- Is hospital admission being considered?
- Has the person had an unplanned hospital admission in the last year?
- Has the person been supported by a crisis team or similar to avoid a hospital admission in the last year?

National policy also emphasises the need for Clinical Commissioning Groups (CCGs) and commissioners to continue to maintain and develop this proactive approach to monitoring and intervention. This is because:

- it requires close, collaborative working across Health, Education and Social Care to enable an improved understanding of the local population and facilitate joint working;
- it assists commissioners to monitor individuals, identify existing gaps in current service provision and design; and
- it enables partnership working with relevant stakeholders, to consider the types of resource required to provide more robust community-based alternatives.

Factors that may place someone at risk of admission

Factors that may put someone at risk of hospital admission could include:

- significant life events and/or change such as bereavement or abuse;
- unstable/untreated mental illness;
- pain or distress from physical health issues (both diagnosed and undiagnosed);
- previous history of inpatient admission(s);
- anyone subject to the provisions of the Mental Health Act (MHA) or Deprivation of Liberty Safeguards (DOLS);
- presenting increased or significant episodes of behaviour that challenges;
- being supported in an unstable environment or by a changing staff team;
- not being previously known to learning disability services;
- having no fixed address;
- being in contact with the Criminal Justice System (CJS);
- presenting 'in crisis' at Accident and Emergency (A&E) department;
- having no family carers/advocates;
- having drug and alcohol addiction problems;
- having no effectively planned transition from child to adult learning disability services;

- being placed in specialist 52-week residential schools;
- having recently been discharged from long stay hospital beds;
- being in receipt of services from youth offending teams; and
- those in receipt of Continuing Health Care (CHC) funding.

(NB: This list is not exhaustive and is based upon local criteria.)

Local Monitoring and Intervention

There are two important components of the CTR system which are used in the community to assess and manage risk and cope with any developing crisis: These are the Dynamic Risk Register and the Local Area Emergency Protocol which are explained below.

Dynamic Risk Register

A Dynamic Register is used by local health and care teams to identify and prioritise the needs of people living with learning disabilities and/or autism who have a mental illness or behaviour that challenges, who may be at risk of admission to a mental health hospital. This might be as a result of a change in needs and/or a failure in their care and support.

The Dynamic Register aims to improve awareness of need and allow more responsive commissioning to ensure that those who need help the most are supported to stay well, have appropriate support to remain in the community and avoid unnecessary admissions to hospital.

Those on the Dynamic Register may be known in a number of ways, including previous contact with local intensive support teams, social care or local authority services, and/or community learning disability teams. They may previously have had periods of inpatient care or be in 52 week residential school placements.

Dynamic Register FAQs

1. Who should be on the Register?

Provided consent has been obtained beforehand, any person with learning disabilities, autism or both who is experiencing the factors listed on page **35** is at risk of inpatient hospital admission and can be placed on the dynamic register.

2. Who decides who goes on the Register?

With appropriate consent, the relevant CCG, LD Complex Needs Panel or equivalent, Multi-Disciplinary Team (MDT) get together routinely to discuss cases in order of need

3. Can parents ask for their son/daughter to be assessed to go on the list?

Yes, this would be welcomed as you are likely to know if there is difficulty arising better than anyone, it is better to have a community CTR to anticipate and reduce the likelihood of a crisis developing.

4. Can families ask for a CTR if their loved one is not on the Register?

Yes (please see above). It may be that the person is not known to services (e.g. someone without a diagnosis or living with 'high functioning' autism who was managing well but a sudden change is causing difficulties).

5. Is the Register for all ages?

Yes, the register is used for children, young people and adults.

6. Is the Register for people with mental health concerns as well?

Yes, if the person has a Learning Disability or Autism.

7. How often are those on the Register reviewed?

Everyone on the register is assessed regularly to make sure that they are getting the help they need. For example, those with the highest priority could be checked daily and others with the least priority perhaps monthly.

8. *Are people told when they are placed on the Register and when they come off?*

Yes decisions must be made with the consent of the person involved.

9. *Is there an official definition of a crisis in this context?*

Anyone at risk of admission to hospital or in need of more support to prevent escalating behaviours that challenge is at crisis point. This may include family/carers or school staff struggling to meet a young person's needs and/or if the young person's change in presentation is putting themselves or others at risk.

10. *If a crisis happens who is responsible for requesting a CTR?*

Anyone who is providing care or support for the person can request a

Local Area Emergency Protocol

The Local Area Emergency Protocol is designed to help health and care services to respond quickly to an unexpected potential crisis that must be dealt with immediately. Anyone involved in the care of a person with learning disabilities, autism or both can raise concerns about an individual who is at risk of being admitted to hospital unnecessarily.

The Protocol lays down how crisis situations are managed if there is no prior knowledge of the escalating risk and no time to hold a community CTR. An emergency meeting should then be organised and chaired by the lead commissioner (either an emergency meeting or teleconference) with the aim of averting the crisis and avoiding an inappropriate admission to hospital.

Due to time limitations, the emergency protocol does not usually involve an independent expert panel (as with CTRs).

What do good outcomes look like?

The National Service Model for Commissioners of Health and Social Care services outlines what local services should look like if they are to effectively meet the needs of children, young people and adults with a

learning disability, autism or both who display behaviour that challenges, including those with a mental health condition.

Although every local area will be different, the service model outlines nine core principles. These are written from the perspective of a person using such services and what they should expect.

| | |
|---|---|
| 1 | I have a good and meaningful everyday life. |
| 2 | My care and support are person-centred, planned, proactive and coordinated. |
| 3 | I have choice and control over how my health and care needs are met. |
| 4 | My family, paid support and care staff get the help they need to support me to live in the community. |
| 5 | I have a choice about where I live and who I live with. |
| 6 | I get good care and support from mainstream health services. |
| 7 | I can access specialist health and social care support in the community. |
| 8 | If I need it, I get support to stay out of trouble. |
| 9 | If I am admitted for assessment and treatment in a hospital setting because my health needs cannot be met in the community, my care and treatment will be of high quality, and I will not stay in hospital longer than I need to. |

Running consistently through all nine principles are five human rights-based outcomes called '**Golden threads**' which should be reflected in local commissioning strategies.

| | |
|------------------------------------|--|
| Quality of Life | Personalised care and support, dignity and respect |
| Keeping people safe | Protecting from harm, openness and positive risk-taking |
| Choice and control | Self-determination and support when needed |
| Support & interventions | These must be provided in the least restrictive manner possible |
| Equitable outcomes | Accessible, reasonably adjusted community-based health and social care |

The National Service Model therefore sets the standard that all Local Authorities and Clinical Commissioners must aspire to in order to satisfy the reasonable expectations of someone who might use such services.

Further Information

Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition

<https://www.england.nhs.uk/publication/service-model-for-commissioners-supporting-people-with-a-learning-disability-and-or-autism-who-display-behaviour-that-challenges-including-those-with-a-mental-health-condition/>

Meeting The Challenge - guides for families: Guides on getting the right support for people with a learning disability and behaviour that challenges

<http://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/assessmentandtreatmentunits.html>

Crisis planning

This section is all about helping families organise themselves to make things easier to manage, even in a crisis.

As previously discussed, (**please see page 6**), there is no one set definition of a crisis: each person will have a different experience of a crisis or emergency. However, in general, a crisis occurs if your loved one does not appear to be coping or to be in control of their behaviour, and/or if you are feel unable to support and keep them or others safe. They may show signs of great emotional distress or anxiety. They may also experience deteriorating mental health, have thoughts of suicide or self-harm, experience hallucinations or be hearing voices.

For anyone living with learning disability, autism or both and whose behaviour is seen as challenging, a crisis can be caused by any number of things, including mental health issues (**please see page 12**), so identifying and managing the cause(s) may be complex.

To meet your loved one's needs effectively, it is important to focus on three things:

- appropriate assessment of needs
- detailed planning, and
- an adequate support network.

In the previous section, we covered avoiding crisis from the 'system' perspective. This section deals with person-centred planning to help your loved one to stay well and avoid the need for crisis intervention.

Crisis Plans

A variety of crisis plan formats have been developed, primarily in the mental health field, to help prevent or manage a crisis. A plan typically consists of a very detailed summary of the person's support network,

likes, dislikes, what things look like when they are well, routines, potential triggers and warning signs.

A crisis plan can be very helpful for families (and other carers) to support their loved ones with learning disabilities and/or autism with any challenges they may face. It can help identify behaviour that is out of character or unusual, and to find coping mechanisms and strategies to help the person cope with the specific situation.

A crisis plan can also help the person, with support if needed, to recognise their own strengths, understand their own triggers and take an active role in their own wellbeing.

A good crisis plan puts the individual at the centre of their health and recovery. It is important to develop the plan with the person's supporters (e.g. parents, carers, health and social service professionals, and care staff) in order to provide support strategies that everyone can use consistently.

None of us can foresee the future, so it pays to try to stay one step ahead. To help your loved one keep well and avoid crisis, it is important to prioritise careful planning and make it part of the everyday routine as much as possible. To tackle this, we recommend something called 'My Backup Plan'. It is similar to a Communication Passport but more in depth. Sometimes these plans are known by different names, such as 'Joint Crisis Plans' or 'Wellness Action Plans'.

My Backup Plan is described below. You can find a blank copy for you to fill in and use if you want to at the end of this guide. [See Appendix A.](#)

Alternatively, you may prefer to use a crisis plan from another source. There are quite a few different versions online. Links to a range of templates can be found under 'Further Information' on **page 41**.

My Backup Plan

My Backup Plan helps your loved one and those around them to think about and write down what they need to stay well, how to identify the signs or triggers that may make them feel unhappy, uncomfortable or unwell, what to do if a crisis occurs and how to get back on track after a crisis.

Using a *Backup Plan* has three benefits

- It helps maintain health and wellness
- It promotes the person's needs and preferences during a crisis.
- It assists with the return to pre-crisis routines.

A blank *Backup Plan* template can be found at **Appendix A**. Once you have filled it in, reading it often will remind you, and others that help and support your loved one, what it is like when they are happy, comfortable and well supported. If anything starts to go wrong, the plan will help everyone put it right quickly.

The format we have used is based on NICE Quality Standard QS14/ Quality statement 9: Crisis planning. This can be found at: <https://www.nice.org.uk/guidance/qs14/chapter/quality-statement-9-crisis-planning>.

The standard identifies eight themes as follows:

- possible early warning signs of a crisis and coping strategies;
- support available to help prevent hospitalisation;
- where the person would like to be admitted, in the event of hospitalisation;
- the practical needs of the person if they are admitted to hospital (e.g. childcare or the care of other dependants, including pets);
- details of advance statements and advance decisions;
- whether (and the degree to which) families or carers are involved;
- information about 24-hour access to services; and
- named contacts.

My Backup Plan includes each of these themes as separate sections with plenty of space to enter the information requested on each page. You will need to look at each page in turn and answer the questions shown. The sections can be filled in to match your circumstances. Attention to detail is very important. Although it will take time to finish it just go through it carefully and avoid rushing it.

Once done, reading each page will help remind your loved one, and everyone providing their support, how best to keep them well and happy and how to help you manage on less good days.

Please note: It is important to involve your loved one in writing the plan as much as possible, and to give them the final say on what is included. They should also decide who receives a copy of the plan.

Further Information

How can I plan for a crisis?

<https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/planning-for-a-crisis/>

NICE Quality standard [QS14] Service user experience in adult mental health services

<https://www.nice.org.uk/guidance/qs14/chapter/quality-statement-9-crisis-planning>

5 top tips for Mental Wellbeing

https://www.rethink.org/media/2770750/wellbeing_guide.pdf

Wellness & Recovery Action Plan templates

Working together for recovery

<http://www.workingtogetherforrecovery.co.uk/Documents/Wellness%20Recovery%20Action%20Plan.pdf>

Recovery Devon: Wellness Recovery Action Plan

https://recoverydevon.co.uk/wp-content/uploads/2010/07/WRAP_Book_A4.pdf

Surrey and Borders Partnership NHS Foundation Trust WRAP:

<https://www.sabp.nhs.uk/application/files/9515/1688/3329/RecoveryWRAP.pdf>

Devon Partnership NHS Trust: Wellness Recovery Action Plan (WRAP)

<https://www.dpt.nhs.uk/resources/easy-read/wellness-recovery-action-plan-wrap>

DR&SH NHS Foundation Trust: My Wellness & Recovery Action Planning® Book

<https://www.rdash.nhs.uk/wp-content/uploads/2014/04/LD-WRAP-Book-April-13.pdf>

My WRAP Plan

<https://namiaustin.org/wp-content/uploads/2014/09/Developing-a-WRAP-Plan.pdf>

Wellness Recovery Action Plan (WRAP)

<http://www.workingtogetherforrecovery.co.uk/Documents/Wellness%20Recovery%20Action%20Plan.pdf>

Personal Crisis Plan (Advance Directive)

<http://mentalhealthrecovery.com/wp-content/uploads/2015/07/CrisisPlan2012Manual.pdf>

Advance Care Planning

Advance Care Planning (ACP) enables someone to make future plans for their care and treatment should they become unable to make decisions at any time in the future because of an illness. It is entirely voluntary and no one is under any pressure or obligation to make advance decisions.

Due to the complexity and legal basis of the process, it is not practical for us to cover ACP in detail within this guide. However, we did feel it was important to explain the difference between an Advance Statement and an advance decision and to introduce crisis cards.

What is an Advance Statement?

An advance statement allows someone to make general statements, describe their wishes and preferences about future care should they be unable to make or communicate a decision or express their preferences at that time. An advance statement is not legally binding. However, those making a 'best interests' decision on the person's behalf should take its contents into account if the person is unable to tell them what they would like.

What is an Advance Decision?

An advance decision allows someone to decide now about specific treatments that they do not want to receive in the future. Its purpose is to ensure that, if they are not able to make decisions at the time, they are not forced to receive treatment that they would not want.

What are Crisis Cards?

A crisis card is designed to be carried in someone's pocket or wallet. It should contain information about what to do and who to contact if the person is experiencing a crisis. They can be very useful if the person has difficulties communicating your distress. You can read an example at:

https://www.cnwl.nhs.uk/wp-content/uploads/CNWL_Single_Point_Access_Crisis_Card.pdf

Further Information

Planning for your future care

<http://www.ncpc.org.uk/publication/planning-your-future-care>

Advance decisions, advance statements and living wills

https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs72_advance_decisions_advance_statements_and_living_wills_fcs.pdf

ReSPECT: Recommended Summary Plan for Emergency Care and Treatment

<https://www.respectprocess.org.uk/>

Advance care plans: Examples of document templates

<http://advancecareplan.org.uk/examples-document-templates/>

Crisis services, cards and plans

<https://www.dpt.nhs.uk/i-need-help-now/what-are-crisis-services-crisis-cards-and-crisis-plans>

Crisis Card App.

<http://myhealthapps.net/app/details/476/Crisis-Card>

Getting the right support

In this section, we have put together some tips and ideas to help you in your caring role. We have also given an overview of the teams that can provide advice and support (routinely or in crisis) to maintain your loved one's care in the community.

Be prepared for anything

If you have a son or daughter with a learning disability, autism or both with behaviour that challenges, you do not need us to tell you that attention to detail is vital. No matter how busy or tired we are, it is important to try to be as organised as possible.

Planning and record-keeping will really help you manage from day to day and cope if things start to wrong. It will also facilitate discussions with education, health or care professionals when they are called on to help. It is a good idea to keep key documents together in one place, including the contact details of all those providing care and support. This will help all those involved to work more effectively, both individually and as a team. Most importantly, it will help everyone to meet your loved one's needs.

Maintain plans and records

There are a number of helpful documents to help support someone with a learning disability, autism or both, whose behaviour may challenge. Some of these are listed below.

- Communication/Hospital Passport
- Positive Behaviour Support (PBS) Plan
- Health Action Plan (HAP)
- Person-Centred Care Plan (PCP)
- Social Care Plan
- Activity Planner

- Education Health & Care Plan (EHCP)
- Health & Care Diary
- Contacts List
- Crisis Plan

All these are explained in this section.

Communication Passport

A Communication Passport contains information about a person with a communication difficulty. It can be used to help the person explain to others how they prefer to communicate and what is important to them. It can help staff, carers, medical personnel or anyone who is in contact with the person, to get to know that person better. Here are some examples:

- This is me: My Care Passport
<http://www.surreyhealthaction.org/assets/files/My%20care%20passport%20-%20enabled%20adobe%20reader%202.pdf>
- Communication Passport (A book about me)
<http://www.brightpart.org/documents/communicate/Communication%20passport%20A4.pdf>
- Health Passport (Homerton)
<http://www.homerton.nhs.uk/media/631143/Homerton-hospital-passport.pdf>
- My hospital passport (National Autistic Society)
<https://www.autism.org.uk/about/health/hospital-passport.aspx>
- This is my Hospital Passport
http://dudleygroup.nhs.uk/wp-content/uploads/2014/08/HOSPITAL_PASSPORT_VERSION_2013_NOV1.pdf

- **Multi Me** (a secure social platform and online person-centred toolkit that helps individuals and families build their own Circles of Support through the sharing of multimedia, secure messaging, goal setting and event planning)

<https://www.multime.com/>

Positive Behaviour Support Plan

This topic has been covered earlier in the section about '**Living with behaviour that challenges**'. To recap, PBS is an approach that is frequently recommended in the support of someone who exhibits behaviour that may challenge those around them. Detailed assessments can be undertaken to try to understand the cause(s) of the behaviour and strategies developed to help better meet the person's needs, in order to avoid the underlying cause of any challenging behaviour.

Once the behaviour(s) are understood and strategies developed, a PBS plan can be developed and then adopted by all those providing support.

Further Information

Positive Behaviour Support Planning Challenging Behaviour Foundation

<https://www.challengingbehaviour.org.uk/learning-disability-files/03---Positive-Behaviour-Support-Planning-Part-3-web-2014.pdf>

Positive Behavioural Support: Practical Tools to help you PBS Academy/CBF

<http://pbsacademy.org.uk/wp-content/uploads/2016/03/Final-Resource-5-PBS-Academy-family-pack.pdf>

Health Action Plan

A Health Action Plan (HAP) is a personal plan used to record all the things that a person needs to remain healthy, including any help needed to achieve it.

An HAP will contain a lot of personal information, such as:

- all about me;
- who supports your loved one to stay healthy;
- how they communicate;
- medical history and diagnosis;
- medication;
- any sensory needs;
- mobility, physical or mental health concerns;
- problems eating and drinking;
- diet and exercise;
- a list of health appointments tests and check-ups; and
- Most importantly, an action plan that lists what needs to be done and when.

The plan will usually be developed and written by the Primary Care team led by the GP, the patient or the health facilitator, and with the help of carers and supporters as appropriate.

Make sure that the GP has recorded your loved one's disabilities and medical conditions on the GP Practice computer system to help them understand their needs. This is called 'flagging'. Your loved one will then be offered an annual health check as well.

If you are a carer, make sure this is recorded as you will also be entitled to a regular health check. A carer is anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support.

At the annual health check, your loved one's GP and/or the Practice Nurse will go through questions and carry out all the checks needed. These are updated on the GP practice computer system. Once this has been completed, an HAP can be printed off and given to you to keep. If you have any questions, or think something might have been left out, ask your GP or Practice Nurse straightaway.

Share the completed Plan with everyone who supports your loved one so you can all work together to make sure that their health needs are met. You can find out more about getting support from your doctor at:

<https://www.mencap.org.uk/advice-and-support/health/dont-miss-out>

Further Information

My Health Action Plan Surrey Health Action

<http://www.surreyhealthaction.org/health-action-planning-made-easy/my-health-action-plan>

Health Action Plan NHS South West Essex and Essex County Council

http://www.southend.nhs.uk/media/67663/health_action_plan.pdf

Person-Centred Care Plan

Person-centred planning helps a person plan all aspects of their life. Putting the person at the heart of their care gives them the opportunity to take control of the things that are important to them and the outcomes that they want to achieve. It is an ongoing process requiring regular reviews to make allowances for any changes of need or priority.

Further Information

Personalised care and support planning NHS England

<https://www.england.nhs.uk/ourwork/patient-participation/patient-centred/planning/>

What person-centred care means Royal College of Nursing

<https://rcni.com/hosted-content/rcn/first-steps/what-person-centred-care-means>

Writing good care plans: A good practice guide Derbyshire
Healthcare NHS Foundation Trust & Care Coordination Association
[http://oxleas.nhs.uk/site-media/cms-downloads/
Writing_Good_Care_Plans_Oxleas.pdf](http://oxleas.nhs.uk/site-media/cms-downloads/Writing_Good_Care_Plans_Oxleas.pdf)

Care and Support Planning Helen Sanderson
[http://helensandersonassociates.co.uk/person-centred-
practice/care-support-planning/](http://helensandersonassociates.co.uk/person-centred-practice/care-support-planning/)

Social Care Plan

Local Authorities are required to assess needs and provide social care services for anyone who meets certain criteria. The assessment must be provided to all people who appear to need care and support, regardless of their financial situation.

If the person is found to be eligible, a Care Plan should then be co-produced by the appointed Social Care professional working together with the person, their parents and supporters as appropriate.

Further Information

Children

Getting social care services when your child has additional needs Contact
[https://contact.org.uk/media/778843/
getting_social_care_services_for_your_disabled_child_i
n_england.pdf](https://contact.org.uk/media/778843/getting_social_care_services_for_your_disabled_child_in_england.pdf)

Adults

The Care Act: assessment and eligibility SCIE
[https://www.scie.org.uk/care-act-2014/assessment-
and-eligibility/](https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/)

Assessment, Eligibility and Support Planning Disability Rights UK
<https://www.disabilityrightsuk.org/assessment-eligibility-and-support-planning>

Care Act Factsheets Department of Health & Social Care
<https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets>

Care and support statutory guidance Department of Health & Social Care
<https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

A guide to the Care Act 2014 and other laws
https://www.hft.org.uk/our-services/family-carer-support-service/fcss-updates/a-guide-to-the-care-act-2014-and-other-laws/?utm_source=fcssnetwork&utm_campaign=careactresource

Activity Planner

An activity planner is a simple grid or timetable on which planned events and activities are recorded for a predefined period. The planner can be drawn up by the person based on their wants and needs, assisted by their carers and supporters, if appropriate. Predictability and routine are often reassuring and empowering, so this also gives the person more control over their daily lives.

Formats vary and there are plenty available of templates online. In a formal care environment, providers may have their own forms and templates. In other settings, a straightforward grid may suffice, such as the one you can find at: <https://www.teachingideas.co.uk/planning/editable-timetables>.

Education Health and Care Plan

Introduced as a part of the Children and Families Act 2014, an Education Health and Care Plan (EHCP) outlines the education, health and social care needs for children and young people aged up to 25 who meet the criteria, and the provision required to meet those needs.

Further Information

Education, Health and Care plans Contact

[https://contact.org.uk/advice-and-support/education-learning/education-health-and-care-\(ehc\)-plans/](https://contact.org.uk/advice-and-support/education-learning/education-health-and-care-(ehc)-plans/)

Education, health and care plans in England National Autistic Society

<https://www.autism.org.uk/about/in-education/extra-help-in-school/england/ehc-plans.aspx>

Education, Health and Care plans **IPSEA**

<https://www.ipsea.org.uk/pages/category/education-health-and-care-plans>

Health and Care Diary

Maintaining a Health and Care Diary can be immensely useful in tracking variations in moods, behaviours and medical symptoms, alongside any changes to strategies and treatments. Keeping a record of health-related appointments, interventions and changes in symptoms or behaviour can be helpful in keeping track of everything. It will help you give accurate information to your doctor or anyone else involved in your loved one's care. It will mean that any decision-making is based upon accurate information rather than relying on memory.

There are a number of diary templates and apps you could download and use, depending upon the device you are using. It can be very effective to create and manage your diary on a computer with a word processing programme (if you have access to one) as you can record anything you need to and you can retrieve information easily by searching for 'key words'. A simple three column table format can work well. Please see **Appendix B** for a basic example you can change it to suit your needs.

Do not forget: if you keep an electronic diary, always keep a backup copy.

Contacts List

When your loved one has a disability and may be in regular contact with a number of health, education and care professionals, it is a good idea to keep a comprehensive list of their contact details in one place. Otherwise, it can be very frustrating having to wade through loads of emails, letters or reports to track down someone's phone number or email address if you already have 101 other things to do.

There are many address book templates and apps available for download on the internet. You can also create one on a computer, if you have access to one.

There is a suggested template you could use at [Appendix C](#), which includes columns for: name, job title, organisation, address, telephone number and email address. Again, always keep a backup copy just in case.

Crisis Plan

In the previous chapter, we introduced a document called *My Backup Plan*. Although it is a lengthy document, we strongly recommend that you complete and add it to your 'Important Documents' folder.

As previously explained, a *Backup Plan* enables you to record details of routines, early warning signs and triggers, coping strategies, support network details, and care and support needs/preferences during a crisis. For more information, please go to [My Backup Plan](#) here.

The [Backup Plan](#), [Contacts List](#) and [Health and Care Diary](#) templates can be found by clicking above.

Keeping track of things

Sometimes being closely involved can make it hard to see a situation clearly as a whole and think objectively about it. It can be helpful to imagine you have been asked to review another family, very like yours, to work out if their situation is sustainable. If it is not, identifying where the

gaps in support and provision are and what needs to be done to fill them is invaluable.

Consider the following questions. If the answer to any of the questions is no, write a short summary of the problem so you can discuss it with your support team. This will help to identify and develop potential solutions.

Questions to help you keep track

- Are your loved one's health needs being met and are there any gaps?
- Are your loved one's care needs being met and are there any gaps?
- Are your (the carer) health and care needs being met?
- Is the current situation sustainable?
- Are all plans and assessments up to date? (This includes care reviews, carer assessment, annual health check and routine checks as per the health action plan.)
- Are any significant events or changes in circumstances planned?
- Is there help available in a crisis? (For example, family, contingency, support network)
- Is a Crisis Plan in place?

Making a Complaint about services

If your experience of services falls short of your expectations or things go wrong, it is important to follow the complaints procedure (every service will have one) to register your dissatisfaction. Complaints policies and procedures should be advertised on the organisation's website.

Depending on who you are corresponding with, the way in which disapproval is recognised and dealt with can vary. Some organisations operate a tiered system that incorporates concerns, comments, feedback and formal complaints. If you are making a formal complaint, it is therefore crucial to make sure that you state this clearly. Check the complaints policy to ensure that any formal complaint is not downgraded without your knowledge. It is also important to keep records of all

correspondence and a diary of events for reference. These will help if you decide to escalate your complaint later on.

Further Information

Here are some links to further resources including independent review options, ranging from the Patient Advice and Liaison Service (PALS) right up to Judicial Review (subject to formal and legal process).

Patient Advice and Liaison Service PALS

<https://www.nhs.uk/chq/Pages/1082.aspx?CategoryID=68>

Making a complaint to your GP or hospital The Patients Association

<https://www.patients-association.org.uk/making-a-complaint-to-your-gp-hospital>

Feedback and complaints about the NHS in England

<https://www.nhs.uk/nhsengland/complaints-and-feedback/pages/nhs-complaints.aspx>

Complaining about the NHS Citizen's Advice

<https://www.citizensadvice.org.uk/health/nhs-and-social-care-complaints/complaining-about-the-nhs/>

Parliamentary and Health Service Ombudsman

Make final decisions on complaints that have not been resolved by the NHS in England and UK government departments and other public organisations.

<https://www.ombudsman.org.uk/>

Judicial Review

<https://www.equalityhumanrights.com/en/advice-and-guidance/judicial-review>

Complaints about social care services

<https://www.citizensadvice.org.uk/health/nhs-and-social-care-complaints/complaining-about-social-care-services/>

Complaints about Special Educational Needs

Contact the Education Department at your Local Authority.

Ask Listen Do : Making conversations count in health, social care and education

Making feedback, concerns and complaints easier for families and carers of children, young people and adults with a learning disability, autism or both

<https://www.england.nhs.uk/wp-content/uploads/2018/06/Ask-Listen-Do.pdf>

When people can't agree: Special educational needs and disability (SEND) complaints: A guide for Young People in education 16 to 25

<https://councilfordisabledchildren.org.uk/help-resources/resources/when-people-can't-agree---special-educational-needs-and-disability-complaints>

Dealing with meetings

When attending meetings, it is important to remember families know and love their child best. As a parent, you have known your loved one since birth, and hold much more information than any professional report could possibly capture. This means you have a deep understanding of your loved ones' needs, strengths and hopes, and that it is important to trust your instincts.

We have already stressed the importance of being organised to help manage everything routinely and to make sure you are ready with all the information you need when meeting with others involved (e.g. Education, Health or Care professionals). Meetings can be stressful, especially if you are taking your son or daughter with you. Just the thought of trying to get them there may fill you with anxiety, with likelihood of them cooperating ranging from very unlikely to impossible.

If there are likely to be any difficulties, let the organiser know well before the meeting. It is important that you can all work together to try and make the adjustments that your loved one might need – and that includes what you might need as their carer. If they have not met you before, it is helpful to send the organisers a communication aid (e.g. 'About Me' summary or Communication/Hospital Passport) to help start the conversation about your loved one's needs.

Ahead of any planned health intervention at hospital, always send the Hospital Passport to the relevant liaison staff so they can prepare accordingly.

Depending upon your loved one's diagnosis and your local NHS arrangements send it to the Hospital learning disability liaison team, the autism liaison service (if available), designated lead, care team or relevant department.

Further Information

Visiting the Doctor

<https://www.autism.org.uk/about/health/doctor.aspx>

My hospital passport

<https://www.autism.org.uk/about/health/hospital-passport.aspx>

Please note: remember that public sector organisations are obliged to make 'reasonable adjustments' for people with disabilities (including learning disability and autism) so it is important for them to know about your loved one's needs.

<https://www.hft.org.uk/resources-and-guidance/disability-rights-and-legal/equality-act/>

Getting ready

Whatever the meeting is for, it is a good idea to be prepared before you go.

- Read through any relevant papers and reports beforehand.
- Write down a list of the questions you would like to ask.
- Collect together the key documents, as well as your loved one's Health and Care Diary for reference.
- Check out your transport and travel arrangements to minimise setbacks.
- Make sure you know exactly where you are going and how to get there.
- Remember that your loved one's consent may be required if they are aged 16 or over (please see the **Glossary**).

Tip: If the meeting is located somewhere new, type in the postcode on Google Earth. Looking at the destination on street view can help you to find your way.

At the meeting

In our busy lives, we all have to attend routine meetings for all sorts of things and hopefully the majority of these will not cause you to worry. However, if you are anxious about anything specific, or if it is a significant meeting, it is a good idea to take someone with you for support (e.g. a partner, spouse, relative or friend). Make sure you let the person organising the meeting know who is coming so they are aware.

It is important to try to keep as calm as possible. This may be easier said than done, especially if you are feeling apprehensive. However, trying to stay calm will help you express all the things you want to.

It is also important to try to maintain good working relationships with the other people at the table as far as possible. Try to stay as positive as you can, as this will hopefully encourage others to focus positively and get things done. Having said that, you are the person who knows your loved one's needs better than anyone else and have every right to put them first in any discussion.

Before the meeting starts, check its expected finishing time so that you can pace yourself accordingly. Make notes during the meeting if you want to and ask the professionals to explain anything you do not understand. Professional meetings can often be littered with acronyms and professional jargon. It is important that these are explained to families. This guide also has a Glossary section (please see [here](#)) to help explain some of the more common ones.

At the end of the meeting, agree on a list of key points and actions to make sure that things happen in the way that you expected. It is likely that you will be sent a summary afterwards, ask about this and details of any further tests or meetings to be held.

If things did not go to plan, for example if there was not enough time or you forgot something, remember you can ask for a follow-up call after the meeting.

Further Information

Education - A guide to making conversations with schools count for all families

<http://www.sendgateway.org.uk/r/makingconversationswithschools.html>

SENDIASS: Making Meetings Matter - Some tips for parents and carers

<https://www.suffolk.gov.uk/assets/Children-families-and-learning/special-educational-needs-and-disabilities-SEND-and-the-Local-Offer/Making-Meetings-Matter.pdf>

How to look after you too

To avoid a crisis, looking after your own needs is just as important as looking after the person you care for. You are important. Read on for a summary of the things you need to be thinking about.

Caring for a family member is often seen as nothing unusual and something you just do if a person that you love needs support. Some might say 'I am not a carer I am just their partner/husband/wife/father/daughter'. Some might say 'As a family member, it is my duty to care for them'. This is how families work of course, and caring for loved ones can be such a positive and rewarding experience. A family member might feel safe in the knowledge that they will always be there and do their best to meet their loved one's needs because they care about them, as well as care for them. It also might mean less worry because they can trust themselves to looking after their loved one properly.

Keep track of your own needs

While you as a family carer are likely to focus on your caring role the most, it is vital that you do not neglect or forget your own needs. Caring can be difficult and tiring work. Carer's groups often warn of the potential negative impact of caring. This can include: loneliness, social isolation, anxiety, frustration, and depression, lack of sleep, money worries and sometimes low self-esteem. It is a long list!

It therefore can be helpful to carry out a separate audit of your needs as a carer. This is so important because a crisis can also result if your own needs are not being met properly. Have a look at the four questions below. If you answer no to any of them, read the following information, click on the links for more information and hopefully get it sorted:

<https://carers.org/article/taking-care-yourself>

Questions to consider

- Have you had a Carer's Assessment in the last 12 months?
- Have you told your GP that you are a carer?
- Have you asked your GP Practice about having a health check?
- Have you got a Carer's Emergency Plan?

Get a Carer's Assessment

Being a carer can be an isolating and demanding experience, which can have a significant impact on health and welfare over time if your own needs are not met along the way.

All carers are entitled to a Carer's Assessment. It is not compulsory, but is a good way to focus on your own needs, which often tends to be the last thing we worry about. The Carer's Assessment is just about you and it can be arranged separately or at the same time as your loved one's Care Review, whichever you wish.

To arrange for an assessment, contact your Local Authority Adult Services department if the person you care for is 18 or older. If you are a parent carer of a person under 18, contact your Children and Young People's Services.

Further Information

Carer's assessments Carer's Trust

<https://carers.org/article/carers-assessment>

Time to think about you

<https://carers.org/timetothinkaboutyou>

Factsheet: Carers' Assessments in England for parents/carers of children with a learning disability

<https://www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-carers-assessments-in-england-for-parents-carers-of-children-with-a-learning-disability/>

Eligibility criteria for carers with support needs under the Care Act 2014

<https://www.scie.org.uk/care-act-2014/assessment-and-eligibility/eligibility/criteria-carers-needs.asp>

Look after your physical health needs

Making the most of your GP Practice

General Practice is evolving to try and keep pace with increasing demand and dwindling resources. The arrangements your practice makes may therefore vary to meet the local need.

The roles and the number of staff involved can also vary according to the size of the practice. These could include: resident or locum GPs, practice manager, pharmacist, practice nurse, healthcare assistants, admin staff. There may also be a number of specialist clinics for things like: diabetes, respiratory illness, antenatal care, family planning and 'Well Women'. There may also be access to therapists, district nursing and paramedics.

Another development is the increasing use of Practice Champions. These are members of staff who have a skill and interest in a particular topic, such as learning disability, dementia and carers.

Tell your GP that you are a carer

Make sure your GP Practice makes a note of your loved one's current diagnoses and disability and also your carer status on their computer

system. This is called 'Flagging' and is important so that all the health staff with access to the system can see what your needs are straightaway. Find out more about how to help your GP help you here:

<https://www.carersuk.org/help-and-advice/health/looking-after-your-health/your-gp>

Make an appointment

Depending upon your GP Practice's local arrangements, there may be a number of ways that you can get help from the Practice Team to meet your needs. When you call to make an appointment, staff will explain the options available and make sure you are seen by the right person. If you need to see the GP, an appointment can be arranged. You may be able to arrange a same-day telephone call back from the GP if you have a pressing need. Find your local GP Practice here:

<https://www.nhs.uk/Service-Search/GP/LocationSearch/4>

NHS Health Check

Unlike the Annual Health Check, which is for people with disabilities, the NHS Health Check is available for anyone between 40 and 74 without a pre-existing condition (e.g. stroke, heart disease, diabetes or kidney disease.) If you would like one, ask your GP Practice. These are designed to check for things like early signs of stroke, heart disease or Type 2 diabetes and should happen once every 5 years.

You can find out more about NHS health checks here: <https://www.healthcheck.nhs.uk/>.

To find out what happens at an NHS Health Check click here:

<https://www.nhs.uk/conditions/nhs-health-check/what-happens-at-an-nhs-health-check-new/>.

Look after your mental health needs

Enduring tiredness, stress and anxiety can wreak havoc on your emotional health and mental wellbeing. If you are concerned about changes in the way you have been thinking or feeling over the past few weeks or months, it is important to see your GP.

Symptoms may include:

- Loss of appetite
- Trouble sleeping, or sleeping too much
- Not enjoying life as much as before
- Feeling low, irritability or moody
- Feeling constantly anxious or worrying
- Finding it harder than usual to concentrate
- Thinking negative thoughts about yourself, and
- Seeing or hearing things that other people do not

Try not to worry about seeing your GP if you have been experiencing some of the symptoms listed above. Supporting patients with their mental health concerns is something doctors do regularly in their Practices. Time with your GP is short, so make some notes before the appointment about the things you want to discuss. The doctor will ask you about your caring role to see if you are getting the support you need for both your loved one and you. He or she may prescribe some medication to reduce your anxiety and stress, or refer you for counselling or a specialist service. Some Practices have access to a counsellor or you could be referred to something called Improving Access to Psychological Therapies (IAPT) which provides evidence-based psychological therapies to people with anxiety disorders and depression where you can have sessions with a trained counsellor.

Further Information

How to talk to your GP about your mental health

<https://www.mentalhealth.org.uk/sites/default/files/how-to-talk-to-your-gp-about-your-mental-health.pdf>

How to cope when supporting someone else

<https://www.mind.org.uk/information-support/helping-someone-else/carers-friends-family-coping-support/your-mental-health/#.W6fqpDGouUI>

Talking Therapy IAPT

[https://www.nhs.uk/Service-Search/Psychological-therapies-\(IAPT\)/LocationSearch/10008](https://www.nhs.uk/Service-Search/Psychological-therapies-(IAPT)/LocationSearch/10008)

SANE offers emotional support and information to anyone affected by mental health problems.

• *Helpline:* http://www.sane.org.uk/what_we_do/support/helpline/

• *Textcare:* http://www.sane.org.uk/what_we_do/support/textcare/

• *Online support forum:* http://www.sane.org.uk/what_we_do/support/supportforum/

Samaritans

<https://www.samaritans.org/how-we-can-help-you>

Emergency planning for carers

It is not pleasant thinking about what might happen if for whatever reason you were suddenly unable to care for your loved one. We have covered emergency planning from the perspective of the person you care for on **page 41**. This section is just about **you**.

Contingency planning is something we cannot ignore and as they say it is better to be safe than sorry. So, what can you do now to prepare, just in case?

Getting a backup carer

You may have a family member or friend who would be able to look after your loved one if you cannot for whatever reason. Discuss what is involved with them and if they and your loved one are both comfortable with this 'backup' arrangement, give your stand-in all the information they will need relating to your loved one and their care needs. Make sure they

know where the emergency plan and other care and support documents are kept.

Making a carer's emergency plan

A Carer's Emergency Plan is essential as a means to summarise and share all your key information in one document. The completed plan can be shared with your backup carer and others involved in providing replacement care and support. You can also place a copy prominently in your loved one's home (i.e. where someone else is likely to find it) if you are not around. The NHS has a Carer's Emergency Plan template that you can download and fill in. You can find out more at:

https://www.nhs.uk/CarersDirect/guide/emergencies/Documents/CD_Emergency_Plan.pdf.

What to include in your emergency plan

If you prefer to develop your own version, here are topics to consider:

- name, address & contact details of yourself, the person you care for and next of kin;
- emergency contact details of people who can provide replacement care;
- your loved one's medical condition(s) and support needs;
- any medication your loved one is taking and any ongoing treatment;
- any communication and mobility issues your loved one may have;
- details of any health professionals involved;
- key information about your loved one's home including access;
- details of any Carer's Emergency Plan registered with the local authority;
- details of legal arrangements (e.g. deputyship or power of attorney); and
- details of any advance care planning.

What if backup family care is not available?

In an emergency, if you can't find anyone to provide backup care, the next option is to ring the Social Services Emergency Duty Team at your Local Authority.

Explain the situation and ask for help. If you have had a Carer's Assessment before, or your loved one has had a Care Assessment, the

assessor should have asked about emergencies and what arrangements are in place if you are ill or have an accident. If you are eligible, replacement care could be provided while you are incapacitated.

Find your local Council here: <https://www.gov.uk/find-local-council>.

It is possible that your GP or district nurse might be able to arrange temporary nursing care at short notice. This is called a Rapid Response Service in some areas of the UK. Referrals for this service have to be made through your loved one's healthcare professionals.

Carer's Emergency Card scheme

Your Council may have a Carer's Emergency Card scheme, so have a look on your Council's website if this is something you might be interested in. Once you have registered with the scheme, someone will help you draw up an emergency plan. You will be given a card to carry around with you which has telephone number to call and a unique identification number.

The Emergency Card can be kept in your purse or wallet, and will help to let other people, such as a first responder or paramedic, know that you are a carer and there is someone at home that relies on you. If anything happens to you, someone else can call the contact number and quote the identification number when asked. The people running the scheme can then access your emergency plan and make arrangements for replacement care. You can add the scheme's details to your written emergency plan.

More information on emergency schemes for carers is available here: <https://carers.org/article/emergency-schemes-carers>.

'In Case of Emergency' cards

A range of commercially produced 'In Case of Emergency' (ICE) cards can be purchased from a company called Smart Technology Systems Limited. These cards can help emergency staff quickly find who to contact in an

emergency. The credit card size ICE cards have clear 'EMERGENCY' text and a first aid logo on one side. On the card's reverse, you can write in who should be contacted in the event of an accident or incident. You can then carry the card with you in your wallet or purse wherever you go. Go to the website for further information by clicking here: <https://www.icecard.co.uk/>.

Tip: You can also store your emergency contact numbers in your phone using the word ICE1, ICE2, and so on. This will mean that, if the emergency services are called to help you, they can check your phone and call the important people straightaway.

Carer's Allowance and emergencies

If you are unable to care for your family member because you're ill or in hospital you can still claim Carer's Allowance for up to 12 weeks.

Build yourself a 'circle of support'

Building and maintaining your own 'safety net' can help make sure that you too are supported. This will enable you to sustain your caring role and make sure that you do not end up running on empty and becoming unwell. This section suggests some ways you can build and maintain your own 'circle of support'.

Develop and maintain a network of helpers

- Are there family members or friends that can help out with caring or running errands for you? If so, let them know how they can help.
- Ask your GP Practice about local carer support groups and services.
- Have you had a carer's assessment in the past 12 months or a reassessment if your needs have changed? If not, contact your local authority about a new assessment.
- Check out your local authority website as they will have details of all local care and support services. Search for 'carers support' or similar.

Tip: Jointly is an app that makes caring for someone a little easier, less stressful and a lot more organised, by making communication and coordination between those who share the care as easy as a text message. Find out more here: <https://www.jointlyapp.com/#welcome>.

Seek out Respite Care

Respite Care is a way for you to have a break from caring. This might involve a paid carer coming in for a few hours a week or your loved one spending some time during the day or overnight somewhere nearby. If you have already been assessed by your local authority, respite should have been considered already. If not, or if your loved one's needs have changed, contact your social services department again. You can find out more about carer breaks and respite care here: [https://](https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care/)

www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care/.

Speak with your employer

If you are working, continuing to work could be very important to maintain your wellbeing. If you are having difficulty managing your caring and work responsibilities, explore whether flexible working is an option for you. Even if it is not feasible, it is important to let your employer know about your situation, so they are aware of the additional strain you're under. You can find out more about flexible working here:

<https://www.citizensadvice.org.uk/work/rights-at-work/flexible-working/flexible-working-what-is-it/>.

Ask about 'Shared Lives'

Shared Lives is a scheme that links people who need help and support with approved families and carers who are willing and able to provide that help and support in their own home. People who use the service may have a learning disability, a physical disability, a mental health problem, or be unable to live independently because of their age. Shared Lives can

be set up to provide day support, respite care, kinship, short-term or long-term care. Find out more about Shared Lives here: <https://sharedlivesplus.org.uk/home/about-shared-lives>.

To find your local scheme have a look on the Local Authorities' website. Find out more here: <https://www.gov.uk/find-local-council>.

Find community support

No matter where you live, there will be a range of opportunities in your local community. These can provide much-needed social and practical contact, and support (e.g. carers groups, community and day centres, lunch clubs, charity run groups, church-based groups and volunteers offering related help).

Further Information

You can find out more about your local organisations, carer support groups, social enterprises and sign up for their newsletters and information bulletins by searching the websites below for local information.

Community Support

Find your local Council

<https://www.gov.uk/find-local-council>

Find services near you

<https://carers.org/search/network-partners>

Support where you live

<https://www.carersuk.org/help-and-advice/get-support/local-support>

Find Carers services in your area

<https://www.nhs.uk/Service-Search/Carers/LocationSearch/1796>

Tackling loneliness

<https://carers.org/article/tackling-loneliness>

How to cope with loneliness

<https://www.mind.org.uk/information-support/tips-for-everyday-living/loneliness/#.W6oO5DGouUk>

Carer support

Carers: help and support

<https://www.citizensadvice.org.uk/family/looking-after-people/carers-help-and-support/>

Being in Control: Getting Personal Assistants (PAs)

<https://www.disabilityrightsuk.org/being-control-getting-personal-assistants-pas>

Respite care

Carer breaks and respite care

<https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-breaks-and-respite-care/>

Getting a break

<https://carers.org/article/getting-break>

Telephone support

Hft: Family Carer Support Service

Free-phone helpline: **0808 801 0448** Tuesday to Thursday from 9am to 4pm.

(Leave a Voicemail if the help-line is busy out of hours. Call back within 7 working days).

Or email **familycarersupport@hft.org.uk** (Response within seven working days)

Carers Trust

<https://carers.org/contact-us>

SANE Mental Health Charity

<http://www.sane.org.uk/home>

Samaritans: A listening ear 24 hours a day

<https://www.samaritans.org/>

Counselling

Counselling Directory

<https://www.counselling-directory.org.uk/>

Counselling for carers

<https://carers.org/article/counselling-carers>

Talking therapy and counselling

https://www.mind.org.uk/information-support/drugs-and-treatments/talking-therapy-and-counselling/#.W69-S_ZFx9A

Coping with loneliness

<https://www.mind.org.uk/information-support/tips-for-everyday-living/loneliness/#.W6oO5DGouUk>

Conclusion

We hope that you have found this guide informative. We have tried hard to use our combined lived experience to help families make sense of the complicated health and care system, which we all have to work with. We hope that it will empower families and help them cope in sometimes extremely difficult circumstances.

Caring for a loved one with a learning disability and/or autism brings with it fresh challenges each day. Knowing how and where to get help and information, or even what questions to ask, can sometimes be really hard. Getting the help you are entitled to can be a lifeline and why we wanted to write this guide.

Finally, we wanted to leave you with a few important things to remember and reflect on.

Personal Survival Tips

- You cannot do it all on your own.
- Asking for help is not a sign of failure.
- Your needs are important too.
- Get yourself a carer's health assessment (if you meet the criteria).
- Look after yourself and don't give in to self-doubt.
- Whatever you do, do not neglect your health.
- Take time out even if it's for only a few minutes at a time.
- Get some help from those around you if you can.
- It is good to talk – stay in contact with family and friends.
- Be organised - keep your paperwork in one place.
- Make sure that your loved one's care needs have been formally assessed by your Local Authority.

More Personal Survival Tips

- Behaviour is a form of communication.
- Do not take the behaviour personally, it is likely a cry for help.
- Do what you can to retain respectful relationships with the health and care professionals you meet. Try not to make enemies!
- Remember - knowledge is power.

Acknowledgements

The deepest debt of gratitude goes to Ian Penfold, without whom this guide would not have happened. Quite how he has managed to fit in writing this guide with all the other work he does to help many other families of people with learning disabilities and autism is a mystery to us all. Thanks too to Isabelle Garnett for co-authoring autism-related sections in the guide.

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Appendix A: My Backup Plan

Introduction

My Back-Up Plan is designed to help your loved one, and those around them, to think about and write down what they need to stay well. It will help to identify the signs or triggers that may make them feel unhappy, uncomfortable or unwell, as well as what to do if a crisis occurs and how to get back on track after a crisis.

The Plan is written from the point of view of your loved one and is arranged in sections that you can work through, one at a time. Simply look at each page in turn and answer the questions according to your loved one's circumstances. If anything does not apply, leave it blank and move on. If you run out of space in any section, you can photocopy or print extra blank page(s).

Once you have finished, reading the relevant pages will help remind you, and those that support your loved one, how best to keep them well and happy, and how to help them manage on 'less good' days.

It is really important to work with your loved one and to ensure they have the final say on what is included and who receives a copy of the plan.

Attention to detail is very important. Just go at your own speed and do not rush completing it.

Urgent Help

If you are worried about the immediate safety of your loved one, and they are at risk of hurting themselves or others around them, take one of the following actions, depending upon your circumstances.

- If you have already been given a Crisis Line number from a health professional, ring them straightaway.
- If you are under the care of a mental health team and have a specific care plan that states who to contact when you need urgent care, follow this plan.
- If the situation is urgent but not life-threatening, book an emergency appointment with your GP or call 111 for advice.
- If there is an acute immediate threat to life, Visit A&E or call 999.

NB: this information is based on *Dealing with a mental health crisis or emergency:*

<https://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/mental-health-emergencies.aspx>

References

This Backup Plan template is based upon NICE Quality standard [QS14]: Quality statement 9: Crisis planning: <https://www.nice.org.uk/guidance/qs14/chapter/Quality-statement-9-Crisis-planning>

NICE guideline NG54: Mental health problems in people with learning disabilities: prevention, assessment and management provides additional relevant information about what good care and support looks like, including the identification and assessment of a potential mental health problem in those living with a learning disability.

<https://www.nice.org.uk/guidance/ng54/chapter/Recommendations>

Downloads

You can download this Appendix A, B & C either as a word document or a pdf.

Word document:

Appendix A:

<http://bringingustogether.org.uk/appendix-a/>

Appendix B:

<http://bringingustogether.org.uk/appendix-b/>

Appendix C:

<http://bringingustogether.org.uk/appendix-c/>

PDF Document:

Appendix A

<http://bringingustogether.org.uk/wp-content/uploads/2019/01/Appendix-A.pdf>

Appendix B:

<http://bringingustogether.org.uk/wp-content/uploads/2019/01/Appendix-B.pdf>

Appendix C:

<http://bringingustogether.org.uk/wp-content/uploads/2019/01/Appendix-C.pdf>

My Backup Plan

NB: The information contained within this plan is personal and confidential and is to be accessed and used by authorised users only.

| | |
|------------------------------|--|
| This plan belongs to: | |
| Name | |
| Address | |
| Telephone No. | |
| Date of birth | |

I developed this plan on (date) _____ with the help of _____

This plan takes over from any with an earlier date.

| | | |
|--------------------------|------------|------|
| My Plan | Print Name | Date |
| | Sign | |
| Witness 1 | Print Name | Date |
| | Sign | |
| Witness 2 | Print Name | Date |
| | Sign | |
| Legal Rep / LPA / Deputy | Print Name | Date |
| | Sign | |

Please note: If the person named in this plan has been assessed as lacking in mental capacity, a best interests decision will be necessary before it can be activated

Who can see my Plan

I want the following people to have a copy of My Backup Plan

| | |
|-------------|--|
| Name | |
| Role | |
| Contact | |
| | |
| Name | |
| Role | |
| Contact | |
| | |
| Name | |
| Role | |
| Contact | |
| | |
| Name | |
| Role | |
| Contact | |
| | |
| Name | |
| Role | |
| Contact | |
| | |

Weekly Routine

Make a list of things that help you feel well on a daily basis. For example, list activities that you enjoy: hobbies, sports, music, arts, regular exercise, making contact with loved ones and those around you, going out and about, chilling out...

| Activities | Day of the week |
|------------|-----------------|
| | Monday |
| | Tuesday |
| | Wednesday |
| | Thursday |
| | Friday |
| | Saturday |
| | Sunday |

All About Me

What is important to me?

What do people like and admire about me?

How best to support me?

| | |
|---|---|
| Supervision | (Staffing, DoLS, CTO, CPA etc.) |
| Protocols | Emergency medication protocols in place |
| Allergies | |
| Cultural needs | |
| Next of Kin | Name Address Telephone number |
| Nearest Relative <i>(appointed under the Mental Health Act)</i> | Name Address Telephone number |

Triggers

Triggers are things that may make you feel unhappy, uncomfortable or unwell. Examples could include things like: physical illness, relationship problems, bad news, worrying about something, feeling overwhelmed and vulnerable, or an unwelcome change of routine. Identifying your triggers and developing plans to deal with them will help you stay well.

Write down your list of triggers below:

Coping strategies

To help you stay well, it's important to work out how best to stop any triggers from making you feel unwell. Have a look at your list of triggers on the previous page. Then write down how best to cope with each one below.

As you go through each one in turn, it might be helpful to have a look at the weekly routine activities section on page 87 to see if doing any of the activities listed could help you cope with the situation? Are there any others that you can think of?

List these 'coping strategies' below:

Possible early warning signs of a crisis

If you start to feel unwell, it is very important for you or those around you to notice the early warning signs to help prevent you becoming ill. Examples could include things like: mood or behaviour changes, unusual thoughts and negative feelings, irritability, withdrawal, difficulty sleeping or an increase in sleeping.

Write down your warning signs below:

| | | |
|-------------|--|--|
| Name | | |
| Role | | |
| Contact | | |
| Name | | |
| Role | | |
| Contact | | |
| Name | | |
| Role | | |
| Contact | | |
| Name | | |
| Role | | |
| Contact | | |
| Name | | |
| Role | | |
| Contact | | |

Support available to help prevent hospitalisation

| | | |
|-------------|--|--|
| Name | | |
| Role | | |
| Contact | | |
| <hr/> | | |
| Name | | |
| Role | | |
| Contact | | |
| <hr/> | | |
| Name | | |
| Role | | |
| Contact | | |
| <hr/> | | |
| Name | | |
| Role | | |
| Contact | | |
| <hr/> | | |
| Name | | |
| Role | | |
| Contact | | |
| <hr/> | | |
| Name | | |
| Role | | |
| Contact | | |
| <hr/> | | |

Where you would like to be admitted in the event of hospitalisation

List below the treatment facilities where you prefer to be treated or hospitalised, if that becomes necessary. At the bottom of the page, list any that you want to avoid.

| Name of Unit | Contact Person | Phone No. |
|---|----------------|-----------|
| <p><u>I prefer this facility because:</u></p> | | |
| <p> </p> | | |

| Name of Unit | Contact Person | Phone No. |
|---|----------------|-----------|
| <p><u>I prefer this facility because:</u></p> | | |
| <p> </p> | | |

| Name of Unit | Contact Person | Phone No. |
|---|----------------|-----------|
| <p><u>I prefer this facility because:</u></p> | | |
| <p> </p> | | |

Write down below any treatment facilities that you want to avoid.

| Name of Unit | Address |
|---|---------|
| <p><u>Reason to avoid using:</u></p> <p> </p> | |

What are your practical needs if you are admitted to hospital

This could include responsibilities such as childcare or the care of other dependants, including pets.

Write in all your practical needs below:

Details of advance statements and advance decisions

Advance care planning is entirely voluntary, and no one is under any pressure or obligation to make advance decisions.

Please look at the table below. If you have any of these documents in force, please enter the information requested to help keep track of everything.

| | | |
|--|-------------|-----------------|
| Advance Statement | Date signed | Enter date here |
| Held by: Name | Address | Tel No |
| Print/Sign | | |
| Advance Decision | Date signed | Enter date here |
| Held by: Name | Address | Tel No |
| Print/Sign | | |
| Lasting Power of Attorney | Date signed | Enter date here |
| Held by: Name | Address | Tel No |
| Print/Sign | | |
| Court of Protection Deputy | Date signed | Enter date here |
| Held by: Name | Address | Tel No |
| State: Health & Welfare (H&W) and/or Finance (FIN) Print/Sign | | |
| Will | Date signed | Enter date here |
| Held by: Name | Address | Tel No |
| Print/Sign | | |

The degree to which families or carers are involved in your Plan

On this page, write down the names of everyone who is helping you so that they can all work well together successfully.

| | |
|-------------|--|
| Name | |
| Role | |
| Contact | |
| <hr/> | |
| Name | |
| Role | |
| Contact | |
| <hr/> | |
| Name | |
| Role | |
| Contact | |
| <hr/> | |
| Name | |
| Role | |
| Contact | |
| <hr/> | |
| Name | |
| Role | |
| Contact | |
| <hr/> | |
| Name | |
| Role | |
| Contact | |
| <hr/> | |

Information about 24-hour access to services

Write in here all your crisis and emergency contacts:

| | |
|-----------------|--|
| Name | |
| Department/role | |
| Contact | |
| <hr/> | |
| Name | |
| Department/role | |
| Contact | |
| <hr/> | |
| Name | |
| Department/role | |
| Contact | |
| <hr/> | |
| Name | |
| Department/role | |
| Contact | |
| <hr/> | |
| Name | |
| Department/role | |
| Contact | |
| <hr/> | |
| Name | |
| Department/role | |
| Contact | |
| <hr/> | |

Treatments and Complementary Therapies

List treatments that help reduce your symptoms and when they should be used:

Treatment/Complementary Therapy

When and how to use this treatment/complementary therapy

Treatment/Complementary Therapy

When and how to use this treatment/complementary therapy

Treatment/Complementary Therapy

When and how to use this treatment/complementary therapy

Treatment/Complementary Therapy

When and how to use this treatment/complementary therapy

My Support Documents checklist

| <i>Please tick all documents in use. Keep everything together in one place along with this Plan.</i> | Tick |
|---|-------------------------------------|
| My Backup Plan | <input checked="" type="checkbox"/> |
| Communication Passport | <input type="checkbox"/> |
| Hospital Passport | <input type="checkbox"/> |
| Current Medications | <input type="checkbox"/> |
| Medication Chart | <input type="checkbox"/> |
| Medication Protocols | <input type="checkbox"/> |
| Risk assessments | <input type="checkbox"/> |
| Mental Health Act papers | <input type="checkbox"/> |
| Mental Capacity Assessments | <input type="checkbox"/> |
| Positive Behaviour Support Plan | <input type="checkbox"/> |
| Behaviour Management Plan | <input type="checkbox"/> |
| Person-Centred Care Plan | <input type="checkbox"/> |
| Activity Planner | <input type="checkbox"/> |
| Health Action Plan | <input type="checkbox"/> |
| Education Health & Care Plans | <input type="checkbox"/> |
| SEN Support Plans | <input type="checkbox"/> |
| Child in Need Plan | <input type="checkbox"/> |
| Looked After Child Care Plan | <input type="checkbox"/> |
| Any relevant youth justice assessment or plan | <input type="checkbox"/> |
| Ministry of Justice documents (where appropriate) | <input type="checkbox"/> |
| The community service specification | <input type="checkbox"/> |
| The community service specification and/or discharge plan. | <input type="checkbox"/> |
| Nursing Assessment | <input type="checkbox"/> |
| Occupational Therapy report | <input type="checkbox"/> |
| Speech and Language Therapy Assessment | <input type="checkbox"/> |
| Advance Care Plans | <input type="checkbox"/> |

Appendix B: Contacts

My Contacts List

Keep track of all your important support contacts in one place.

| | | |
|----------------|------------------|---------------------|
| Name | Job Title | Organisation |
| Address | Telephone | Email |
| | | |
| Name | Job Title | Organisation |
| Address | Telephone | Email |
| | | |
| Name | Job Title | Organisation |
| Address | Telephone | Email |
| | | |
| Name | Job Title | Organisation |
| Address | Telephone | Email |
| | | |
| Name | Job Title | Organisation |
| Address | Telephone | Email |
| | | |
| Name | Job Title | Organisation |
| Address | Telephone | Email |
| | | |
| Name | Job Title | Organisation |
| Address | Telephone | Email |
| | | |

Appendix C: Diary

My Health & Care Diary

Record a history of health related appointments, interventions and changes in symptoms or behaviour.

| | |
|---------------------------|----------------|
| Date | Details |
| Observations/Notes | |
| | |
| | |
| | |
| Date | Details |
| Observations/Notes | |
| | |
| | |
| | |
| Date | Details |
| Observations/Notes | |
| | |
| | |
| | |
| Date | Details |
| Observations/Notes | |
| | |
| | |
| | |

My Health & Care Diary

Record a history of health related appointments, interventions and changes in symptoms or behaviour.

| | |
|---------------------------|----------------|
| Date | Details |
| Observations/Notes | |
| | |
| | |
| Date | Details |
| Observations/Notes | |
| | |
| | |
| Date | Details |
| Observations/Notes | |
| | |
| | |
| Date | Details |
| Observations/Notes | |
| | |
| | |
| Date | Details |
| Observations/Notes | |
| | |
| | |
| Date | Details |
| Observations/Notes | |
| | |
| | |

Glossary

Advance Care Planning

Advance Care Planning (ACP) enables someone to make future plans for their care and treatment, should they become unable to make decisions at any time in the future because of an illness. It is entirely voluntary: no one is under any pressure or obligation to make advance decisions.

Advance Decision

Part of Advance Care Planning, an advance decision allows someone to decide about specific treatments that they do not want to receive in the future. Its purpose is to ensure that, if they are not able to make decisions at the time, they are not forced to receive treatment that they would not want.

Advance Statement

Part of Advance Care Planning, an advance statement allows someone to describe their wishes and preferences about future care, should they be unable to make or communicate a decision or express their preferences at that time. An advance statement is not legally binding. However, those making a 'best interests' decision on the person's behalf should take its contents into account if the person is unable to tell them what they would like. It is sometimes known as a Statement of Wishes.

Advocacy

Sometimes it can be difficult to make a decision if the choices are hard to understand, especially if a person has a learning disability. An independent advocate is someone who can help a person make a decision about health care and other things. An advocate helps them to understand what is being proposed, explains the choices available and helps their person to ask questions if they are not sure what to do. An advocate then supports them to make sure that your voice and your final decision are heard loud and clear.

Annual Health Check

Anyone who has a learning disability over the age of 14 can ask for an Annual Health Check (AHC) from their GP Practice. Having an AHC is very important to maintain good health. If you have a learning disability or autism, it can be harder to look after yourself and notice things that might

be a sign of illness. Having this regular review every year provides an opportunity for a thorough check-up. This means that any problems can be identified and treated before they get worse.

Assessment and Treatment Units

An Assessment and Treatment Units (ATU) is a hospital inpatient unit designed to provide hopefully short-term secure placements for people with learning disabilities who have been admitted following a crisis in the community. While in the ATU, their needs are assessed and a treatment programme established, before arranging their discharge into the community, with support if necessary.

Autism

Autism is a term used to describe a group of developmental disorders (also including Asperger Syndrome and Pathological Demand Avoidance) that affect a person across their lifespan, from childhood through to later life. The core difficulties individuals with autism have relate to:

- communication and language,
- social interaction and emotional expression, and
- social imagination.

In addition, individuals with autism may differ from other people in relation to how they process information provided to them verbally or in writing, and their sensory processing may also be different. They may display patterns of restricted and repetitive behaviour. People with autism may experience anxiety, as a result of the core difficulties associated with the condition.

Backup Plan

The Backup Plan included with this guide is designed to help your loved one and those around them to identify what they need to stay well, how to spot the signs or triggers that may make them feel unhappy, uncomfortable or unwell. It helps define what to do if a crisis occurs and how to get back on track after a crisis.

Behaviour Support Plan

A Behaviour Support Plan aims to understand and manage behaviour in children and adults who have learning disabilities and display behaviour that others may find challenging. A good Behaviour Support Plan sets out possible triggers and provides alternative ways of meeting needs to avoid the person resorting to challenging behaviour. All strategies should be based upon the least restrictive principles in relation to managing risk.

Best interest principles

Section 1 of the Mental Capacity Act (2005) sets out the five 'statutory principles' (the values) that underpin the legal requirements in the Act.

Principle 1: A person must be assumed to have capacity unless it is established that s/he lacks capacity.

Principle 2: A person is not to be treated as unable to make a decision unless all practicable steps to help her/him to do so have been taken without success.

Principle 3: A person is not to be treated as unable to make a decision merely because s/he makes an unwise decision.

Principle 4: An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in her/his best interests.

Principle 5: Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Best Interests

If a person is unable to make a decision due to a lack of mental capacity (e.g. consent to medical treatment), any decision must be made in the person's best interests in accordance with the 'best interests' process stated in the Mental Capacity Act (2005). (See above.)

Capacity

Mental capacity is the ability of an individual to make their own decisions. Decisions about mental capacity where there is uncertainty are governed by the Mental Capacity Act (2005). A capacity check has to be for a specific reason and carried out at the time a decision needs to be made, as capacity can fluctuate.

Care Act Assessment

Under the Care Act (2014), Local Authorities have a duty to carry out an assessment of anyone who appears to require care and support, regardless of their likely eligibility for state-funded care. If the person is then found eligible for support, the person has a right to have their assessed needs met.

Care and Treatment Review

A Care and Treatment Review (CTR) is carried out for an adult living with a learning disability and/or autism who is either at risk of admission to, or is an inpatient within, a hospital Assessment and Treatment Unit (ATU). The

aim of a CTR is to: avoid admission wherever possible, make sure that ongoing inpatient treatment meets the person's needs and/or to plan their discharge from hospital.

Care Programme Approach

CPA provides a programme of community care which is managed by a care coordinator in line with an agreed care plan. CPA is for patients who have a mental health problem, a learning disability or who are otherwise vulnerable and need additional support in the community to stay safe and well.

Care Plan

A Care Plan sets out in detail how a person's needs are to be met. The Plan is then used by all those involved to ensure there is continuity of care, and needs are met appropriately and consistently.

Care Review

A Care review is held to check that a person's current needs are being met. The review will be carried out with the organisation responsible for providing the care and support.

Care, Education and Treatment Review

A Care, Education and Treatment Review (CETR) is a review carried out for a child or young person (under the age of 18) living with a learning disability and/or autism who is either at risk of admission to, or is an inpatient within, a hospital assessment and treatment unit (ATU). The aim of a CTR will be to: avoid admission wherever possible, make sure that ongoing inpatient treatment meets the child or young person's needs or to plan their discharge from hospital. A CETR is the same as a CTR but also includes education alongside health and care.

Carer's Assessment

All Carers are entitled to have their needs assessed. The assessment will look at how caring affects your life and how to address your own physical, mental and emotional needs. It will also ask whether you wish to carry on caring, or whether there are any aspects of the caring role that you feel unable to continue with or take on. Contact adult social services at your local council and ask for a carer's assessment.

Carer's Emergency Card

Your Council may have a Carer's Emergency Card scheme, so have a look on your Council's website. Once you have registered with the scheme, someone

will help you draw up an emergency plan. You will then be given a card to carry around with you, which has telephone number to call and a unique identification number. The people running the scheme can then access your emergency plan and make arrangements for replacement care.

Carer's Emergency Plan

Many local carer services and local councils offer carers schemes where an emergency plan can be put into action if there is an emergency. Planning in advance, and talking about who could provide care if this happens, makes an emergency easier to deal with.

Challenging behaviour

As set out in page 14 of *Challenging Behaviour: A Unified Approach*, Royal College of Psychiatrists et al (2007), 'challenging behaviour' is behaviour 'of such an intensity, frequency or duration as to threaten the quality of life and/or the physical safety of the individual or others, and is likely to lead to responses that are restrictive, aversive or result in exclusion.'

Clinical Commissioning Group

A Clinical Commissioning Group (CCG) is a clinically led organisation that has two important roles: they are responsible for commissioning community and secondary care services for their local populations and they have a legal duty to support quality improvement in general practice. Commissioning involves deciding what services are needed for diverse local populations and ensuring that they are provided.

Communication Passport

A Communication Passport contains information about a person with a disability who may also have a communication difficulty. It helps them explain to others how they prefer to communicate and what is important to them. It can help staff, carers, medical personnel or anyone who is in contact with the person, to get to know that person better, provide reasonable adjustments and meet their needs more effectively.

Community Learning Disability Team

A Community Learning Disability Team (CLDT) provides specialist secondary care and support for people with learning disabilities, and their families, if their needs are too complex to be managed by generic services. Teams consist of learning disability community nurses, therapists, a psychiatrist and a psychologist. They provide a range of learning disability-related services including core assessment, physical health, epilepsy, autism, mental health,

dementia, behaviour seen as challenging, therapies, daily living skills, planning and advice, and information, communication and service liaison.

Community Mental Health Team

These support people living in the community who have complex or serious mental health problems. The range of mental health professionals that work in the team can include psychiatrists, psychologists, community psychiatric nurses, social workers, and occupational therapists.

Consent

Before anyone over 16 is given any medical treatment, test or examination, they must provide their consent. Consent can be given by the patient verbally, indicated non-verbally or in writing. It must be obtained voluntarily having provided the patient with sufficient information with which to make an informed choice. For children under 16 and for those who may lack the mental capacity to make the decision, there are additional steps and safeguards in place. In an emergency, obtaining consent may not be necessary.

Continuing Health Care

NHS Continuing Health Care (CHC) is a package of care for adults aged 18 or over, which is arranged and funded solely by the NHS. In order to receive NHS CHC funding, individuals have to be assessed by Clinical Commissioning Groups (CCGs) according to a legally prescribed decision-making process to determine whether the individual has a 'primary health need'.

Crisis Cards

A Crisis Card is designed to be carried in someone's pocket or wallet. It should contain information about what to do and who to contact if the person is experiencing a crisis.

Crisis plan

This is a personal care plan containing essential and detailed information about the care and support likely to be needed to help someone during a crisis. This could include early warning signs, available support to help prevent a crisis, personal care preferences, practical needs, advance planning decisions, an agreed list of personal supporters, and details of crisis services and named contacts.

De-escalation strategies

The use of techniques (including verbal and non-verbal communication skills) aimed at defusing anger and averting aggression. PRN (as needed) medication can be used as part of a de-escalation strategy but PRN medication used alone is not de-escalation (NICE guideline NG10).

Deprivation of Liberty Safeguards (DoLS) – DoLS is part of the Mental Capacity Act and aims to make sure that people who cannot consent to their care arrangements in a care home or hospital are looked after in a way that does not inappropriately restrict their freedom. To deprive a person of their liberty, care homes and hospitals must request standard authorisation from a local authority.

Dynamic Risk Register

A Dynamic Register is used by local health and care teams to identify and prioritise the needs of people living with learning disabilities and/or autism who may also have behaviour that challenges or a mental illness, and may be risk of admission to a mental health hospital. This might be as a result of a change in needs and/or a failure in their care and support.

Education Health and Care Plan

An Education, Health and Care Plan (EHCP) is for children and young people aged up to 25 who need more support than is available through special educational needs support. An EHCP will identify the individual educational, health and social needs and set out the additional support required to meet those needs.

Eligibility

Each Health and Social Care service is contracted and organised to provide a specific range of support and services to those with 'eligible' needs. To work out who may be eligible, an assessment will be completed by the team concerned and a decision made based upon local or national criteria.

Emergency Duty Team

An Emergency Duty Team (EDT) is a service that provides a 24-hour, 7-day-a-week response to emergency situations. They provide help and support where an adult or child in their Local Authority area is at risk of significant harm where it would not be safe, appropriate or lawful to delay the intervention to the next working day.

Flagging

The term 'flagging' means the process of correctly recording all patient disability information by health care staff on their organisation's computer health record system. This is important to make sure that they know what additional help and support patients with disabilities must have to meet their needs. This is called making reasonable adjustments.

General Practitioner

General practitioners (GPs) provide confidential patient consultations and initial medical care for patients of all ages within a community-based setting. GPs have knowledge of a broad range of illnesses, treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment.

Health Action Plan

A Health Action Plan (HAP) is a personal support plan. It states what a person and others around them needs to do to keep them healthy. It lists what services and support they need to live a healthy life and should state clearly who will do what when.

Health and Care Diary

Maintaining a Health and Care diary to record a history of health-related appointments, interventions and changes in symptoms or behaviour can be enormously helpful in keeping track of everything. This will help you to provide accurate information to your doctor or anyone else involved when needed to further inform decision making based upon accurate information rather than relying upon memory.

Hospital Passport

A hospital passport is used by someone with a learning disability and/or autism to share essential personal information about them with hospital doctors and nurses to help them provide the right care and treatment while in hospital. This is especially important if the person has a communication difficulty. The document would typically contain details about things like: health conditions, medication, communication and personal care needs including mobility, likes, and dislikes.

Improving Access to Psychological Therapies

This service provides confidential counselling for adults suffering from depression and anxiety disorders by providing evidence-based psychological therapies including Cognitive Behavioural Therapy.

Learning Disability

A person with a learning disability is someone who, from childhood, has had a significantly reduced ability to understand new or complex information, or learn new skills and has a reduced ability to cope independently. (Valuing People definition.)

Least restrictive principles

The Mental Capacity Act (2005) states that, when making a decision on behalf of someone that lacks mental capacity, any decision must consider if it is possible to decide or act in a way that would interfere less with the person's rights and freedoms of action, or whether there is a need to decide or act at all.

Local Area Emergency Protocol

Part of the NHS England Care and Treatment Programme the local area emergency protocol is used when someone living with a learning disability and/or autism and challenging behaviour is at risk of being admitted to a hospital assessment and treatment unit because of a crisis. An urgent meeting or teleconference will be held to try and help the person to continue to live in their communities with the right support and avoid them being admitted to a hospital assessment and treatment unit (ATU).

Local Authority

A local authority (LA) is an organisation that is officially responsible for all the public services and facilities in a particular area. Their legal duties include the identification, assessment, education and support of disabled children and young people, proving a Local Offer (see below) and the assessment and support of all residents (including carers) who have eligible social care needs.

Local Offer

The Local Offer is a list of services across education, health and social care for children and young adults aged 0 to 25. Each Local Authority is obliged to maintain the list on behalf of residents who have special educational needs or a disability and their families.

By providing all the information in one place the Local Offer will improve choice and transparency for families and also be an important resource for professionals.

Mental Capacity Act

The Mental Capacity Act (MCA) is a law that protects and supports people who may have difficulty in making some of their own decisions. It ensures

that they are given all necessary support to make every decision they are able to make, and to contribute towards any decisions made about their lives that they are unable to make themselves.

Mental Capacity Assessment

Sometimes, as the result of a disability or illness, a person might find it difficult to make their own decisions and need some help. Using the Mental Capacity Act, anyone aged 16 and over can be assessed whether they have the mental capacity to make a particular decision. The person is deemed to lack capacity if they cannot do any of these four things.

- Understand information given to them about a particular decision.
- Retain that information long enough to be able to make the decision.
- Weigh up the information available to make the decision.
- Communicate their decision.

Mental Health Act

The Mental Health Act (MHA) is the law that governs the assessment, treatment and rights of people with a mental health disorder who may be subject to compulsory detention and treatment. The law gives health professionals the powers, in certain circumstances and without consent, to detain, assess and treat people with mental disorders in the interests of their health and safety, or for public safety.

Multi-Disciplinary Team

A Multi-Disciplinary Team (MDT) consists of a number of professionals from different specialties within health and social care, working together to meet the needs of patients with complex needs in their care.

NHS Health Check

The NHS Health Check is available for anyone between 40 and 74 without a pre-existing condition. If you would like one, ask your GP Practice. These are designed to check for things like early signs of stroke, heart disease or type 2 diabetes and should happen once every 5 years.

Occupational therapy

Occupational therapists work with adults and children of all ages with a wide range of conditions (most commonly those who have difficulties due to a mental health illness, physical or learning disabilities) to help them continue with life skills, work and leisure activities. They treat patients through specific activity to enable them to reach their maximum level of function and independence.

One-page profile

A one-page profile is an aid to communication. It provides a one-page summary about a person: who they are, what is important to them and how they wish to be supported. This can help anyone supporting them to provide better person-centred support.

Patient Advice and Liaison Service

Patient Advice Liaison Service (PALS) is an all age, confidential service providing advice, support and information to help patients, families and carers navigate NHS services. PALS staff will be happy to answer questions, hear compliments, comments, concerns or complaints about NHS services and can help to resolve problems by discussing the available options and offering further assistance if required.

Pen picture

A pen picture is a concise summary of who a person is. Typically, it will include personal details, background, experience, skills and qualifications, interests, values and lifestyle. Depending upon the target audience, likes, dislikes, hobbies and interests can be added.

Person-centred planning

Person-centred planning helps a person plan all aspects of their life. Putting the person at the heart of their care gives them the opportunity to take control of the things that are important to them and the outcomes that they want to achieve. It is an ongoing process requiring regular reviews to make allowances for any changes of need or priority.

Physical interventions

The Challenging Behaviour Foundation defines physical interventions as 'any method of responding to challenging behaviour which involves some degree of direct physical force to limit or restrict movement or mobility' (Harris et al, 2008). See more here: <https://www.challengingbehaviour.org.uk/understanding-behaviour/physical-interventions-sheet.html>.

Pica

Pica is an eating disorder where someone has a compulsive desire to eat non-food items, which can of course be very harmful. If this behaviour persists, the cause will require further checks and investigation by a GP. If you are concerned about the safety of someone who has eaten something that they are not supposed to, seek medical help immediately.

Positive Behaviour Support

Positive Behaviour Support (PBS) is a person-centred and structured approach to supporting people with a learning disability and/or autism who display challenging behaviours. PBS focuses supporting positive behaviours and teaching new skills, rather than trying to contain the behaviours. Challenging behaviours are assessed to identify what they mean for the person, and then support is given to develop alternative skills to meet its purpose.

Positive Behaviour Support plan

A Positive Behaviour Support (PBS) Plan is developed, following a functional behaviour assessment, to provide strategies to help understand and manage the challenging behaviour. This results in a better quality of life as the behaviour is not only understood, but also the person's needs are better met without them having to resort to challenging behaviour.

Primary Care

Primary health care is the first point of contact for most people in need of help and advice regarding health issues. The majority of primary care is provided by general practitioners (GPs), but specialists such as dentists, opticians and community pharmacists also provide primary health care. GPs are usually supported in the practice by a nurse, and may have access to other practice professionals such as a pharmacist or occupational therapist.

Rapid Response Service

The purpose of a Rapid Response Service is to provide urgent short term support or rehabilitation at home to avoid a person having to go into hospital. Local provision may vary, but referral will typically be via a GP or other health professional. It may also be available via 111 or a single point of access system, if available. Rapid Response teams consist of nurses, occupational therapists, physiotherapists, and health and care workers.

Reasonable adjustments

If a person has a disability, care providers must make 'reasonable adjustments' to the way in which they provide their services to make sure that you are not disadvantaged and that services are accessible. This could include, for example, providing alterations to building access to cater for wheelchair users, accessible information, longer appointments or booking a person in at the start or end of the day to minimise waiting.

Referral

Many of the more specialist health services are not available directly and a referral has to be made through a lead professional or a GP. This is so that the receiving team can check that they are the correct service and that you meet their criteria for support. On receipt of the referral, a member of the team will get in contact, complete an assessment of needs and then work out how best to help.

Requests for social care support, are also made by a needs assessment through your local authority to work out what help you need and whether you meet the eligibility criteria.

Respite Care

Respite is a way for you to have a break from caring. This might involve someone coming in for a few hours a week, or your relative spending some time during the day or overnight somewhere nearby to give you a break. Respite could be available as the result of a carer's assessment or as a part of your loved one's Care Plan.

Sensory processing difficulties

Many people living with autism have difficulty processing everyday sensory information. Senses may be over- or under-sensitive. Sensory overload can be very distressing and result in withdrawal, challenging behaviour or meltdown.

Shared Lives

Shared Lives is a scheme that links people who need help and support with approved families and carers who are willing and able to provide that help and support in their own home. People who use the service may have a learning disability, a physical disability, a mental health problem, or be unable to live independently because of their age. Shared Lives can be set up to provide day support, respite care, kinship, short-term or long-term care. To find your local scheme, look on your Local Authorities' website.

Smearing

Smearing faeces can occur for many reasons and causes can be medically related, sensory-related or behavioural. A functional assessment will be used to try and determine the cause. Strategies can then be developed provide alternative ways of meeting needs to avoid the person resorting to this behaviour.

Social imagination difficulties

Social imagination difficulties affect people with autism, meaning it can be difficult for them to understand and interpret other people's thoughts, feelings and actions, predict what will happen next or understand the concept of danger.

Speech and language therapy

Speech and language therapy provides treatment, support and care for children and adults who have difficulties with communication, or with eating, drinking and swallowing. Therapy will be led by a speech and language therapist (SaLT).

Transition planning

Preparing a person with an Education, Health and Care Plan (EHCP) for transition to adulthood starts in Year 9 (when a young person is 13 or 14 years' old). An EHCP can continue to age 25 if they remain in education. The local authority must complete a transition assessment before the young person reaches the age of 18 if they are likely to need support from social care. If the child has a primary health need, an NHS Continuing Health Care Assessment should be completed well before their 18th birthday, to allow enough time for the assessment to be completed.

Trichotillomania

Hair-pulling disorder frequently connected with depressive and obsessive-compulsive disorders <https://www.nhs.uk/conditions/trichotillomania/>.

Wellness Action Plan

A Wellness Action Plan is a document written by, with or for someone who needs help in their daily lives to stay well, physically and mentally. This will typically be used by someone with a mental health illness, and can also be of benefit for someone with a learning disability and/or autism who has behaviour that challenges those around them. This Plan enables a detailed record to be made of standard routines, early warning signs and triggers, coping strategies, support network details, and care and support needs/preferences during a crisis.

Acronyms

| | |
|-------|---|
| A&E | Accident and Emergency Department |
| ACP | Advance Care Planning |
| AHC | Annual Health Check |
| ATU | Assessment and Treatment Unit |
| BSP | Behaviour Support Plan |
| CBF | Challenging Behaviour Foundation |
| CCG | Clinical Commissioning Group |
| CETR | Care, Education and Treatment Review |
| CHC | Continuing Health Care |
| CJS | Criminal Justice System |
| CLDT | Community Learning Disability Team |
| CTR | Care and Treatment Review |
| CETR | Care, Education and Treatment Review |
| DoLS | Deprivation of Liberty Safeguards |
| ECHP | Education Health and Care Plan |
| GP | General Practitioner |
| HAP | Health Action Plan |
| Hft | Learning Disability Charity |
| IAPT | Improving Access to Psychological Therapies |
| ICE | In case of emergency |
| IPSEA | Independent Parental Special Education Advice Charity |
| LA | Local Authority |
| MDT | Multi-Disciplinary Team |
| MHA | Mental Health Act |
| NASEN | National Association of Special Educational Needs |
| NDTi | National Development Team for Inclusion |
| NICE | National Institute for Health and Care Excellence |
| OT | Occupational therapy |
| PALS | Patient Advice and Liaison Service |
| PBS | Positive Behaviour Support |

| | |
|----------|---|
| PCP | Person-centred planning |
| SALT | Speech and language therapy |
| SCIE | Social Care Institute for Excellence |
| SEN | Special Educational Needs |
| SEND | Special Educational Needs and Disability |
| SENDIASS | Special Educational Needs and Disabilities Information Advice and Support Service |

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Additional information has been provided indirectly from a wide range of sources in good faith and is believed to be accurate at the time of writing. Referencing this information has been necessary in order to help families understand and make the best use of what is a very complicated process.

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