Action for Carers Surrey – Surrey Young Carers INFORMATION PACK: Neurological Illness June 2020



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1. Introduction

Neurological illness in your family

If someone in your family is diagnosed with a neurological illness, it can appear a bit scary. Not only are you worried about them and what will happen, but you also have to cope with the changes in their behaviour and how they impact you.

In this pack, you will find information on what a neurological illness is, how the condition may affect you, tips on how to look after yourself and who you can turn to for help and support.

2. What is a neurological illness?

Neurological conditions means problems affecting the brain or the nervous system. There are over 470 recognised conditions. Some of these problems start at birth, some are inherited and others happen after illness or injury. Anyone can have a neurological illness at any point in their life.

Families impacted by a neurological illness can have good and bad days. They may have a poor memory and forget things easily, they can get tired and need to rest more than others. They can worry about things and get down. They may have difficulty keeping warm or get too hot.



3. Types of neurological illness

Everyone with a neurological illness will have their own individual symptoms and may not have the same symptoms as someone else with their diagnosed illness, but here is some general information on some of the most common neurological illnesses:

Alzheimer's disease

Alzheimer's disease falls under the illness dementia. This disease affects the brain's memory and this will often get worse over time. Doctors still do not know the exact reason why people get Alzheimer's.

Some of the symptoms your family member may have are:

- Confusion
- Difficulty planning or making decisions
- Difficulty speaking
- Problems moving
- Their personality may change such as being aggressive or demanding
- Low mood or anxiety

Brain injury

There are a lot of different reasons why your family member may have a brain injury, they could have even been born with it or it could have been a more recent illness that you and your family have dealt with.

Some of the symptoms your family member may have are:

- Tiredness
- Sensitive to certain sounds or lights
- Memory loss
- Mood changes
- Feeling sad or anxious

Cerebral palsy

Cerebral palsy is the name for a group of conditions that affect a person's movement and co-ordination. It is usually diagnosed before, during or just after a baby is born and is a lifelong condition.



Some of the symptoms your family member may have are:

- They may be stiff or floppy
- Have weak arms and legs
- Uncontrolled movements or jerking
- Walking on their tiptoes
- Problems swallowing or speaking

4. How does it affect you?

It can be very difficult when someone in your family has a neurological illness and it may impact you in many different ways.

If it's a parent, they may:

- Not be able to give you as much time and attention as you would like
- Have extreme emotions and appear angry with or withdrawn from you or rely on you for emotional support
- Struggle with routines like mealtimes, bedtimes and taking you to school or clubs and activities
- Need extra help with household chores, buying food and paying bills

If it's a sibling, they may:

- Not want to socialise with you
- Have extreme emotions and appear angry with or withdrawn from you or rely on you for emotional support
- Take up a lot of your parents' time and attention

This may make you feel:

- Like you are missing out
- Ashamed, embarrassed or confused
- Worried about them and whether you will suffer from the same illness.

It is very important to remember that these feelings are completely normal. You should never blame yourself or feel guilty for having them.



5. Looking after me

Talk about how you're feeling

You're probably going through a lot of different feelings at the moment. Make sure you talk to your family and friends about these feelings.

Look after your physical health

If you can, try to go out in the fresh air at least once a day, whether that is kicking a ball around with a sibling, going for a walk, throwing a ball in the air and catching it or maybe even a bike ride.

Why not try to cook a meal for you and your family, using healthy ingredients.

Look after your mental health



As well as talking about how you are feeling, why not try and learn something new. Maybe something you have always wanted to, but just never had the time from juggling your caring role and school.

Build a support network

If you are feeling down about everything going on in the world right now, try to limit the time you spend checking the news and try to follow something more positive.

Talk to your friends on a daily basis. If you have previously swapped contact information with other young carers you may have met at Group, contact them and see how they are getting on during this time.

Some activities to try

On the next page, you will find some suggestions for relaxation activities. Why not pick one at random, and give it a go?

My Mindfulness bingo

Go on a mindful, quiet, calm nature walk	Practice mindful eating, how does the food taste?	Notice the details of 3 things you can see right now	Stretch like superman	Close your eyes and take 10 deep breaths
Colour a picture	Close your eyes and listen to calming music	Give someone in your family a hug for 10 seconds	Breathe in like you're smelling a flower, breathe out like you're blowing a leaf	Take a mindful bath and listen to the water running
Close your eyes and think of your favourite memory	Do a dot - to -dot or crossword puzzle	When you wake up take 5 deep breaths	Create a glitter jar	Lay down flat and feel your belly while you breath in and out
Close your eyes and take 10 deep breaths	Balance on one foot while keeping your gaze on something in front of you	Close your eyes and sit in silence for 1-3 minutes	Name 2 things you can smell right now	Name 3 things you can hear right now
Name 2 things you can feel right now	Be a butterfly; sit, bend knees and flap legs like wings	Dance to your favourite song	Jump up and down, then relax with hand on heart. Feel your heart beat	Blow bubbles and watch them float away

These exercises should take between 2-5 minutes each.

When completing the physical exercises try to do these in a peaceful area and remember to breathe deeply through the exercises to help you relax.

Going on a nature walk should be a time to stop thinking and enjoy your surroundings. Notice the grass beneath your feet, take time to inspect the veins of a leaf or the bark from a tree. Smell the different flowers you come across. Look for creepy crawlies.

To make a glitter jar you will need:

- An empty water bottle or jar
- Add a big spoonful of glitter
- Fill it up with water to the top
- Screw the lid back on and shake.

One thing to remember is to enjoy yourself and to take time to reflect.



6. Who can help?

Surrey Young Carers (part of Action for Carers Surrey). Call us on 01483 568269 or email syc@actionforcarers.org.uk And read lots more on our website https://www.actionforcarers.org.uk/who-we-help/young-carers-under-18/

The Brain Charity – offering emotional support, practical help and social activities to anyone with a neurological condition and their family, friends.

www.thebraincharity.org.uk

Telephone 01512 982 999

Headway – is a national charity working to improve life after brain injury. They promote understanding of brain injury and provide information, support and services to people with a brain injury, their families and carers. They have local support in Surrey too: https://www.headway.org.uk/

Telephone 0808 800 2244

YoungMinds – a UK leading charity fighting for children and young people's mental health https://youngminds.org.uk/find-help/looking-after-yourself/coronavirus-and-mental-health/ Text YM to 85258

Anxiety UK – Work to relieve and support those living with anxiety www.anxietyuk.org.uk Telephone 03444 775 774 or 0333 212 5820

Mind- the mental health charity <u>www.mind.org.uk</u> Telephone 0300 123 3393 Find support from Mind near you: <u>www.mind.org.uk/information-support/local-minds</u>

SANE - Provides care and emotional support for people with mental health problems, their families and carers. www.sane.org.uk Telephone 0300 304 7000

Carers UK - Support for carers www.carersuk.org/help-and-advice/get-support
Telephone 0808 808 7777

Find support from Carers UK near you: www.carersuk.org/help-and-advice/get-support/local-support

 $\textbf{Shout}-\text{a 24/7 UK crisis text service available for times when people feel they need immediate support}\\ For support in a crisis <math display="block">\underline{\text{www.giveusashout.org}}$

Text Shout to 85258. Free and anonymous 24/7.

Surrey Young Carers, part of Action for Carers Surrey

Call on 01483 568269 or email syc@actionforcarers.org.uk



Action for Carers Surrey

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