

Supporting Children with Neurological Conditions Coping with COVID-19 Isolation

The next few weeks (and possibly months) will be a particularly difficult time for children and families, whilst schools are closed and we are advised to self-isolate or socially distance ourselves from our friends and family. Our normal structure and routine will be out of the window. This information pack aims to support children and young people with neurological conditions, such as cerebral palsy and help them and their parents to think about different ways of keeping physically well and emotionally positive through these difficult times.

This Booklet was put together by the Children's Occupational Therapy team, with contribution from children's dietetics, physiotherapy, psychology and speech and language therapy services (April 2020)

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1. Introduction - Children and Young People with Neurological Disorders

Government advice suggests (DOH 2020) Children and young people with neurological disorders, such as cerebral palsy, are more susceptible to infections as they often have a compromised immune system. In addition, they may have associated medical conditions such as difficulty with breathing, eating and have epileptic seizures which can interrupt daily routines. People with cerebral palsy are within the population who should be shielded from COVID 19 by staying at home. Keeping well throughout this period of lockdown is critical. During this time, you may continue to need to have specialist health professionals visit your home, to avoid you going into a clinic or hospital. This booklet gives you ideas and strategies to help keep well during COVID 19, signposting you to some resources and specialist services.

Please continue to keep in touch with your health team – we are still here to help.

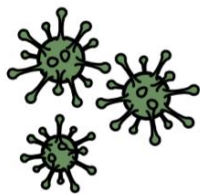
2. Government guidance and Easy-read Information on Covid 19

It is important to help your child understand Covid 19 and there are many resources for parents to access. <https://www.mencap.org.uk/advice-and-support/health/coronavirus>

There are resources that you can work through with your child, to help them understand

<https://www.childcomwales.org.uk/wp-content/uploads/2020/03/Coronavirus-English.pdf>

Hello!



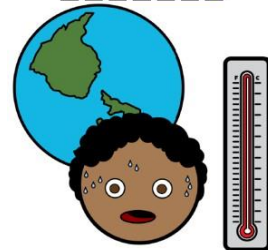
I'm a virus, I'm from the
same family as the Flu and
Common Cold.

My name is Coronavirus.

<http://littlepuddins.ie/coronavirus-social-story/>

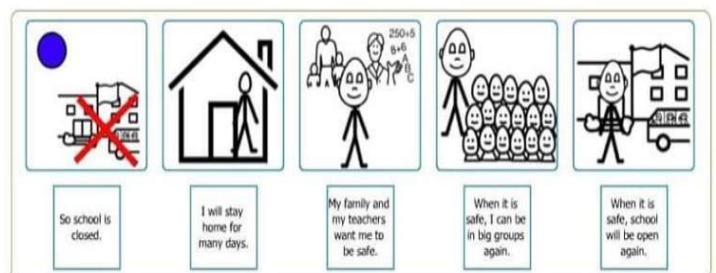
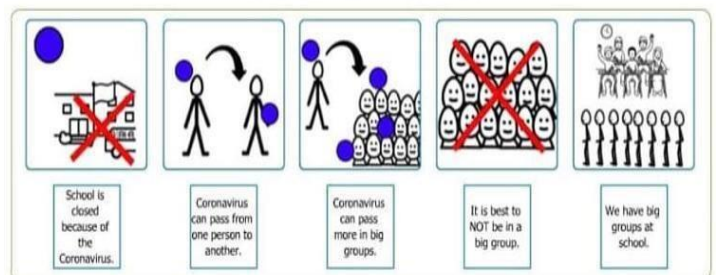
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WHAT IS THE
CORONAVIRUS?



Written by Amanda Mc Guinness

School is closed





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Advice for parents during coronavirus

Whilst coronavirus is infectious to children it is rarely serious. If your child is unwell it is likely to be a non-coronavirus illness, rather than coronavirus itself.

Whilst it is extremely important to follow Government advice to stay at home during this period, it can be confusing to know what to do when your child is unwell or injured. Remember that NHS 111, GPs and hospitals are still providing the same safe care that they have always done. Here is some advice to help:



RED

If your child has any of the following:

- Becomes pale, mottled and feels abnormally cold to the touch
- Has pauses in their breathing (apnoeas), has an irregular breathing pattern or starts **grunting**
- Severe difficulty in breathing becoming agitated or unresponsive
- Is going blue round the lips
- Has a fit/seizure
- Becomes extremely distressed (crying inconsolably despite distraction), confused, very lethargic (difficult to wake) or unresponsive
- Develops a rash that does not disappear with pressure (the 'Glass test')
- Has testicular pain, especially in teenage boys

You need urgent help:

Go to the nearest A&E department
or phone 999



AMBER

If your child has any of the following:

- Is finding it hard to breathe including drawing in of the muscles below their lower ribs, at their neck or between their ribs (**recession**) or **head bobbing**
- Seems dehydrated (dry mouth, sunken eyes, no tears, drowsy or passing less urine than usual)
- Is becoming drowsy (excessively sleepy) or irritable (unable to settle them with toys, TV, food or picking up) - especially if they remain drowsy or irritable despite their fever coming down
- Has extreme shivering or complains of muscle pain
- Babies under 3 months of age with a temperature above 38°C / 100.4°F
- Infants 3-6 months of age with a temperature above 39°C / 102.2°F
- For all infants and children with a fever above 38°C for more than 5 days.
- Is getting worse or if you are worried
- Has persistent vomiting and/or persistent severe abdominal pain
- Has blood in their poo or wee
- Any limb injury causing reduced movement, persistent pain or head injury causing persistent crying or drowsiness

You need to contact a doctor or nurse today.

Please ring your GP surgery or call
NHS 111 - dial 111

The NHS is working for you.
However, we recognise during the current coronavirus crisis at peak times, access to a health care professional may be delayed. If symptoms persist for 4 hours or more and you have not been able to speak to either a GP or 111, then take your child to the nearest A&E



GREEN

If none of the above features are present

- You can continue to provide your child care at home. Information is also available on NHS Choices
- Additional **advice** is available to families for coping with crying of well babies
- Additional **advice** is available for children with complex health needs and disabilities.



Self care

Continue providing your child's care at home. If you are still concerned about your child, call NHS 111 - dial 111



3. What is PPE and why do people need to use it?

PPE is **personal protective equipment**. It is used to keep you and the people who care for you, safe from spreading infection.

While it looks quite strange it is important that this is used to keep us safe

PPE masks can make it very difficult to understand someone which can make it difficult to know what is happening.



Some ideas to help

- *Ask the person to write their name on their apron so you know who it is.*
- *If you have regular carers, put their picture and name on your schedule*
- *Make a schedule of the things they need to do for you and ask them to stick to the routine*

Please don't be scared,
it's only me!
Just being prepared,
come over and see...


Don't I look funny,
I think I look good
In my gloves, my gown
and my spaceman hood!

But why do I wear this
I can hear you say,
Why of course it's to keep
all those germs away!

They won't come near
cos I'm safe as can be
To take care and protect you
so just follow me

Bye bye nasty germs,
you can't get me!
My spaceman nurse will help
to keep me germ free!

Love from Phoenix Ward!
Written by Jackie Crane



4. Reducing the spread of infection

It's more important than ever that regular and thorough hand washing is followed to prevent the spread of COVID 19 and other infections. Take time to follow hand washing instructions and make sure every time your carers come to help you with something, they wash their hands before approaching you or wear hygienic gloves.

Protect yourself and others from getting sick

Wash your hands



- after coughing or sneezing
- when caring for the sick
- before, during and after you prepare food
- before eating
- after toilet use
- when hands are visibly dirty
- after handling animals or animal waste

 **World Health Organization**





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a. Supporting children dependent on others with hand washing

Some children will need help to maintain hand hygiene, particularly if their neurological condition impacts independence in activities of daily living.

- Make certain your own hands are thoroughly washed and dried first.
- Wear gloves if this is your usual routine/protocol.
- Check any individualised recommendations, including specialist equipment that helps body positioning to enable washing routines.
- Do not force the child/young person's hands, fingers or thumb to open or move, but slowly apply, gentle-but-firm handling.
- If possible, immerse the child/young person's hand in a bowl of warm soapy water and gently place your thumb into the palm. Starting at the baby finger, work towards the index finger using small rotating movements.
- This can help to ease/release the fist to wash between web spaces of the fingers and hand creases.
- Wash one hand at a time to limit any associated movements or tonal changes.
- If appropriate, introduce handwashing during the day as part of sensory-motor play activities.

Handwashing tips for children with muscle tightness/joint stiffness

Handwashing can be more difficult if you have increased muscle tone (tightness) or joint stiffness that affects your wrist-hand/finger position or movements. If you experience mild to moderate muscle tightness that makes it harder to open your hand, try to adopt a body/upper limb position that usually helps relax tone e.g. sitting. Distraction may also help e.g. listening to music, chatting to someone. If it is easier try using a bowl on your lap, floor or a table, rather than the sink and use hand washing as an opportunity for water play with bubbles!



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Take care to cleanse in between fingers and other creases in your hands. Ask for help if needed.
Don't forget to dry hands thoroughly.



Hand Washing Tips for People
With Sensory Difficulties
<https://www.sensoryintegration.org.uk/News/8821506>

NHS hand washing song
<https://www.youtube.com/watch?v=S9VjeIWLnEg>

Workbook for children about
hand washing
<https://www.schuelke.com/gb-en/news-media/LD-Hand-Hygiene-Course-handout.pdf>

Baby shark Hand washing Song
<https://www.youtube.com/watch?v=72cNRdyan8>

b. Children wearing Hand Splints or Orthoses

Continue to wear hand orthoses as recommended by your local therapist as it may help maintain range of movement and ease of access for hand washing

If your child uses hand orthoses/hand splints it is important to wash the splint as well as your child's hand. Wash splints daily or wipe them over with anti-bacterial wipes if your child has touch surfaces which may have been infected by COVID 19



c. Don't forget your face

Some children will be dependent on others to wash their face and help them maintain hygiene during coughs, sneezes, tears and runny noses. Other children and young people, like adults, habitually touch their face, particularly if seeking out self-regulating or exploratory experiences. While it is important to nail handwashing, bear in mind touching potentially infected surfaces and spreading this to eyes/mouth/nose can be reduced by regular hand, face, and home hygiene practice.



d. Oral hygiene

It is very important to keep your child's mouth and teeth clean to help stop chest infections, particularly if your child has eating and /or drinking difficulties. Aim to brush teeth at least twice a day. If your child has high calorie nutritional supplements, it helps to brush teeth after giving these as well. Use a small soft dry toothbrush with a 'pea' sized amount of non-foaming toothpaste (Sodium lauryl sulfate free) such as 'Aquafresh Children's Little Teeth



(1400ppm). Do not rinse afterwards and do not use any mouthwash. Dry any excess liquid/saliva with a soft cloth.

It is important to keep gums clean with a small soft dry brush/cloth even if your child has no teeth.

Apply a water-based moisturiser to the lips and just inside the lips every 2-3 hours.



5. Routines and New Habits

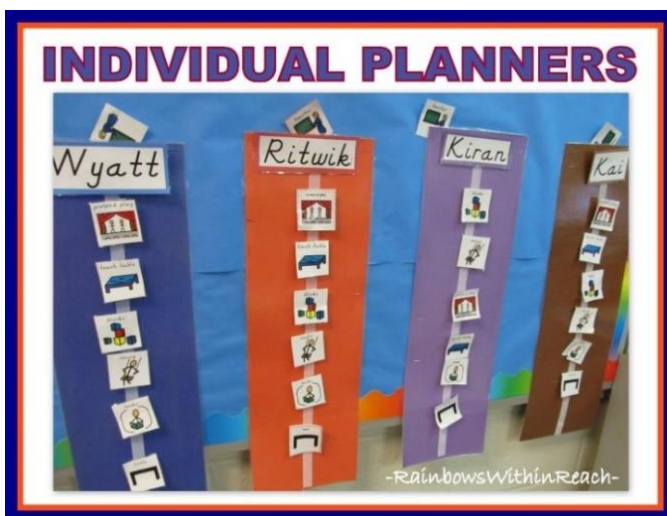
Keeping to familiar routines throughout the day, as best as possible, adds predictability and certainty to the child/young person's world. Try to keep the same waking/personal care/dressing, eating and bedtime habits.

Setting new routines

During COVID 19 your usual daily routines will have changes and will need to be adapted. Creating a daily/weekly schedule can reduce uncertainty, which in turn will help reduce anxiety. A predictable day can support feelings of security and potentially reduce the potential for children to need to control all activity and interaction around them.

There are three key elements or occupations, which make up our day. These are the **things we need to do, have to do, and want to do**. A balance of these three occupations helps us keep physically and emotionally well. For instance, we **need** to eat, keep clean and sleep to sustain our health; we **have** to go to school or work to gain skills for life or contribute to society; we **want** to have time to relax and do things just for fun. With schools closed the routine of 'have to do' tasks has been disrupted and while home school guided by your child's school is essential, you can also look to chores within the home to build in 'have to do' occupations.

A new schedule together for weekly or daily activities can separate occupations and maintain a healthy balance within our daily routines, some ideas to structure this are attached below. Schedules or planners can be in words or pictures relevant to the child/young person's age and/or understanding. Daily schedules can also reflect what is manageable by caregivers, with breaks, quiet time or choice time added.



Home Learning Schedule			
8:00	breakfast	2:00	learning time
9:00	exercise	3:00	life skills
10:00	shower / hygiene	4:00	tech time
11:00	learning time	5:00	dinner
12:00	lunch	6:00	quiet activity
1:00	free time	7:00	bedtime

Breezy Special Ed





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





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Schedules can be pinned up somewhere visible and accessible or added into IT software, dependent on your preference. Use a NOW-NEXT-LATER chart to help your child understand the sequence of events and to focus on the task in hand



Examples of ways to schedule your days and week

MORNING 		Waking up and getting dressed	
		Breakfast	
		Teeth cleaning and hands washed ready to start	
		TASK A	
		Break time	
AFTERNOON 		TASK B	
	12.30	Lunch	
		TASK C	
	2.30	Break time	
EVENING 	3.00	Chatting with a friend on video call	
		TASK D	
		Teatime	
		Helping tidy away	
		Play and relaxing	
		Chill out and getting ready for bed	
		Bedtime	

TASK A	TASK B	TASK C	TASK D
School work set by school	Active mind	Keeping fit	Art and craft
Maths	Dominoes	Exercise	Sewing
Writing a diary or a story	Scrabble	Gardening	Woodwork
Construction	Word drop	Going for a walk	Painting and colouring
Music	Cards	Dancing	Singing
Writing a letter	Jigsaw	Obstacle course	Dancing
Card games	0 + X's		
	Karaoke sing-along		
	Playing with dolls		

Choose a different task from each column each day to vary you week

COVID-19 DAILY SCHEDULE

© Jessica McHale Photography

Before 9:00am	Wake up	Eat breakfast, make your bed, get dressed, put PJ's in laundry
9:00-10:00	Morning walk	Family walk with the dog Yoga if it's raining
10:00-11:00	Academic time	NO ELECTRONICS Sudoku books, flash cards, study guide, Journal
11:00-12:00	Creative time	Legos, magnatiles, drawing, crafting, play music, cook or bake, etc
12:00	Lunch	
12:30PM	Chore time	A - wipe all kitchen table and chairs. B - wipe all door handles, light switches, and desk tops. C - Wipe both bathrooms - sinks and toilets
1:00-2:30	Quiet time	Reading, puzzles, nap
2:30-4:00	Academic time	ELECTRONICS OK Ipad games, Prodigy, Educational show
4:00-5:00	Afternoon fresh air	Bikes, Walk the dog, play outside
5:00-6:00	Dinner	
6:00-8:00	Free TV time	Kid showers x3
8:00	Bedtime	All kids
9:00PM	Bedtime	All kids who follow the daily schedule & don't fight



6. Keeping healthy

It is important to keep up-to-date with Government advice <https://www.gov.uk/coronavirus> and Public Health Wales <https://phw.nhs.wales/topics/latest-information-on-novel-coronavirus-covid-19/> to protect yourselves and those you come into contact with.

Here are some other general ideas for keeping well:

a. Looking after yourself in times of uncertainty

Managing anxiety and mindfulness for children with disabilities.

The COVID 19 pandemic has created uncertainty for many people. It is important that we find ways to support self-care. Self-care is key to calming our-selves, so we have the resources (brain power!) to care and support others. We would recommend trying to implement structure, routine, and consistency to your life as well as those you care for! For self-care to be effective it needs to be sustainable and practical for your lifestyle!

It has recently been proven that children with neurological conditions such as cerebral palsy, benefit from **MINDFULNESS** exercises to keep calm. Some main principles of mindfulness include:

- Being in the present moment, focusing on the here and now within your physical environment
- Noticing and increasing your awareness of what is going on around you
- Understanding that everyone may have different ways of being mindful. Do not judge or try and label what is happening, it can be a very individual thing

Mindfulness can be helped by:



Thinking about breathing (see later in this document for ideas to help breathing)



Slow down – helping your child slow down actions, try and be deliberate about movements. Think about movement before it happens and slow thinking



Be patient – mindfulness is a skill and takes time to learn

There are many mindfulness apps available for children on the internet. Some ideas include Smiling Minds <https://www.smilingmind.com.au/mindfulness> Its well worth having a look for some ideas and building mindfulness into your daily routines



YOGA is another technique which is being used more and more with children with cerebral palsy. It links with mindfulness and helps flexibility, strength and can relieve stress

There are many examples of yoga for children with cerebral palsy but before choosing yoga exercises have a chat with your physiotherapist who may be able to flag the exercises which are most accessible for your child

<https://www.cerebralpalsyguidance.com/cerebral-palsy/treatment/yoga/>

DO SOMETHING MEANINGFUL - Think of an activity you enjoy. It can be ANYTHING! Having a long soak in the bath, reading a book, listening to music, going to watch a football match. What is it about the activity that you value? For example, if it's going to watch the football, could you watch football on the TV. Or is it that you like going to the football and miss being with your friends. Maybe skype or facetime call your friend Try to identify what you **value** about the activities you enjoy doing in your life and think about how you can still live your life by these!

b. Nutrition: Eating and Drinking

Having a healthy and balanced diet and regular meals is important for health and wellbeing. Eating a wide range of foods including plenty of fruit and vegetables, starchy food, protein, and some dairy products (or alternatives) will provide a good supply of nutrients. Nutritious snacks can also contribute

Staying well hydrated through drinking, or other modes of feeding, helps keep secretions moist and therefore easier to clear (cough). This is especially important if a child or young person is prone to respiratory problems. Drink at regular periods throughout the day

Do not forget to follow your individual Feeding Plan provided by your Speech and Language Therapist/Dietician. It is important to adopt recommended posture/positioning during mealtimes and if relevant, use prescribed equipment eg specialist seating. If you need to contact your Speech and Language Therapist for feeding advice, please ring Woodlands House on 02921836585 and request contact is made.

Good positioning promotes digestion and reduces the risk of reflux or heartburn. Often children will need to be positioned in an upright posture during feeding eg sitting or standing, to assist and support safe mealtimes with the family.



c. Positioning, 24-hour postural management and home exercises

Children with neurological impairments experience changes in postural tone (stiff arms and legs). These can vary throughout the day or be fixed patterns of movement. Think about how your child is positioned across a 24 hours period as this may help manage their tone; the diagram below may help with this. As part of usual routines during the day, aim to change the child or young person's position regularly.





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Things to remember!

- **PLEASE TRY TO GIVE YOUR CHILD A CHANGE OF POSITIONING EVERY 2 HOURS DURING THE DAY TO GIVE YOUR CHILD A POSTURAL BREAK.**
- **YOUR CHILD MAY ALSO NEED POSTUAL CHANGES THROUGHOUT THE NIGHT.**
- **REGULAR CHANGES OF POSITION WILL REDUCE THE RISK OF PRESSURE AREAS AND PROVIDE COMFORT FOR YOUR CHILD.**
- **WHEN YOU CHANGE YOUR CHILD'S POSITION TRY TO KEEP THEIR BODY IN A GOOD, WELL SUPPORTED POSTURE.**
- **YOUR CHILD CAN HAVE FREE PLAY ON THE FLOOR FOR SHORT PERIODS BUT TRY TO AVOID TWISTED (ASYMMETRICAL) POSTURES.**

Think comfort and symmetry!

It's also important to take time out of postural equipment and stretch, move and play!





**You may be able to offer your child a different position to carry out a daily task.
Examples of positioning for different activities of daily living are shown**

Positioning for feeding	Commercial highchair Specialist seating Standing frame Prop with cushions to support upright and aligned position Sitting in bed
Positioning for sleep	Use different shapes pillows – rolls, v or standard to align and support Use your prescribed day/night positioning system Profiling bed
Positioning for play and posture management	Wedges, pillows and towels rolled into a sausage Using specialist equipment to provide postural breaks e.g. Static seating or standing frame for play/feeding Prone/supine on bed/floor for postural breaks and play Beanbags or specialist moulded P-Pod beanbags for chill out time! Use of recommended splinting and toys to support hand position (see activities at the end of the sheet!)

d. Specialist equipment

If you have specialist equipment to manage your postural needs e.g. to support sitting, feeding, play, standing or sleeping please **remember to visually check it over, each time before use** and attach all lap/chest straps and harnesses as you have been shown. Refer to information from your local therapist e.g. safe use of equipment guide or Seating Passport.

If home equipment does not look or feel safe (e.g. parts have become loose or missing) please contact your local Occupational Therapist or Physiotherapist on Therapies Admin 02921 836910. If the equipment is broken or damaged contact the Joint Equipment Service on 029 20873673

The Wheelchair Service will respond to emergency concerns relating to powered or standard wheelchair provision Tel: 01443 661799

Ensure you clean your child's equipment frequently as dirt and food crumbs will harbor bugs and germs. Pay extra attention to contact areas, handles, armrest, brakes, tray, straps/harness etc.





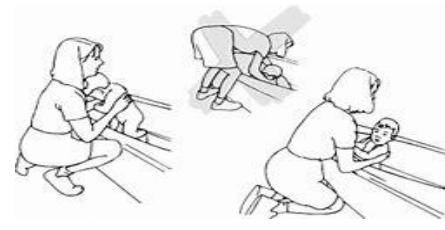
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e. Moving and Handling



In these unprecedented times you may find yourself needing to provide more physical care for your child than usual. **Please refer to your moving and handling advice or plan provided by your occupational therapist. If you have specialist equipment use it if you can and if you need extra advice about equipment use or your child's need changes, contact your occupational therapist**

LOOK AFTER YOUR OWN POSTURE

PRINCIPLES OF MOVING AND HANDLING	BEFORE ATTEMPTING TO MOVE YOUR CHILD THINK ABOUT.....
Avoid bending, twisting, and staying in the same position for long	Does your child need help to move? Can you assist them to use the skills they have?
Make sure you are stable, with feet hip width apart and one foot slightly in front as if you were balancing on a surfboard	Have you told your child you're moving them?
Bend hips and knees to get to a lower height, but not so low you can't get back up.	How heavy are they? Are you healthy enough to move them?
You can bend your back <u>BUT</u> remember to look up when you lift as this will protect your spine	Is there anyone who could help you? If someone does help you, agree your technique and decide who will instruct when to start lifting eg Ready, steady, go
Remember to move, stand and stretch – try to do this before you 'seize up'	How long will it take?
Get as close as you can. Avoid over-reaching and have a firm hold. Keep any weight close to your body	Is there enough space around you? Are there any obstacles in the way, is the floor slippery or damp?
Lift as smoothly as possible and don't try and lift all in one go: if possible, lift in stages	Are you wearing suitable clothing and shoes?
Never lift above shoulder height	Could equipment help – if it's height adjustable position in at the start at a good working height or as close as possible to the destination?
Reduce the number of times you need to move your child by planning your day	When pushing and pulling equipment make sure all the casters are in the same direction before you start. Use a relaxed grip and push in a horizontal movement, bending the hips and knees rather than pushing 'down'



f. Keep moving, keep active!

Keeping active, at regular intervals on a daily basis, is a great way of looking after physical, respiratory and mental health and wellbeing. Opportunities to be active, whether a child/young person is mobile or in a wheelchair should be scheduled in. The link below details activities for children and young people with mobility limitations.

<https://www.specialneeds.com/activities/mobility-limitation/activities-kids-exercises-children-wheelchairs>



Continue with any recommended physiotherapy and occupational therapy programmes you have been provided with from the NHS or those you have arranged to see privately e.g. Bobath.

g. Your breathing

Even if you don't have respiratory difficulties you may find the following suggestions useful as part of general relaxation.

- Take a moment to breathe well and practice deep breathing. Exercise to stretch your chest will help you to expand your lungs capacity. This is a very good strategy to be able cough productively and it will help you get better sooner.
- Aerobic exercise is particularly beneficial to provoke deep breathing, even gently.

If you have a 'chest-physio programme' it is very important to follow, as it could play an important part in helping to keep your chest clear.



The Bobath Centre recommend the following breathing exercises for children with cerebral palsy or other neurological conditions that affect respiratory function.

- *Lie comfortably on your back - if your lower back arches a lot, place one or two pillows under your knees.*
- *Your parent or carer can lift your arms above your head as far as you feel comfortable and possibly prop your arms with additional pillows for support. Once positioned comfortably, focus on taking slow deep breaths and even slower releasing your breath.*
- *Practice for few minutes and then turn on your side and bring on arm up to your ear and breath in the same slow manner into your side for few minutes. Repeat on the other side too.*

<https://www.bobath.org.uk/news/coronavirus-advice-people-cerebral-palsy> [April 2020]

Don't worry about getting into the exact pose at the expense of holding your breath. Work within your abilities – the main thing to focus on is getting deep breaths that will expand your chest. You may need a carer to assist if unable to assume positions yourself.

Breathing using play

Blow bubbles to help with respiratory function and breathing control; try to catch/pop them with fingers; blow a windmills; blow on strips of tissue.

Bubbles can be lots of fun! All you need to do is mix fairy liquid and water and make a wand to dip. The parent blows the bubbles to the child or vice versa. Encourage the child to reach pop the bubbles or blow them. It is not only stimulating but also helping children work their core as they reach up to pop them from a sitting position. To make the bubble wands you can hand craft these with pipe cleaners. This activity also encourages hand-eye coordination.



Sleep

Disruption to typical routines and anxiety can impact sleep hygiene. It is important to understand that the amount of energy you use in the day will impact how tired you are at night. **To help with sleep a child of 5-17 yrs needs min of 60 minutes physical activity a day.**

(World health Organisation)

<http://todaysparent.com/family/activities/15-ways-to-keep-kids-active-indoors-even-if-you-dont-have-much-space/>

The Sleep Foundation provide steps to promoting better sleep, including sticking with your usual bedtime and sleep routines.

<https://www.sleepfoundation.org/sleep-guidelines-covid-19-isolation>

It is important to continue to use prescribed overnight positioning equipment or recommended postures by your local therapist/Dr. e.g. elevated head, raised end of bed.

Some ideas to help get to sleep and stay asleep

- Calming pressure – Use a heavy blanket, a sleeping bag, and/or encouraging your child to hug a pillow - are all calming. If your child is struggling to get to sleep or stay asleep - wrap a quilt cover over the bed and tuck it in tightly either side under the mattress, so their bedding doesn't come off, and they feel snug and tightly tucked in.
- Sensory needs bedwear – Some children wear tighter bed clothing (ie a full protection UV swimsuit), as the deep touch pressure enables them to settle and maintain sleep.
- Keeping it together – If your child has problems with picking at his nappy/pull ups/pads in bed, put press studs on pyjamas so the top and bottom fit together. Or back to front sleep suit on back to front to stop nappy escapologists/ diggers at night.
- Night wanders – If your child wanders during the night, buy a plastic door hook to go over the top of the door and put a mobile that jangles on it. Use this in conjunction with a baby alarm.
- Sleep sac - If your child tosses and turns a lot, which means blankets don't stay on, a sleep sac can help. Or you can use a child sleeping bag for larger children/ young adult.
- Towels & teddy bears for support - When positioning your child at night, spare cushions, pillows, towels and teddy bears will often do a great job of supporting your child in bed. Less space - make a tighter cosier space for your child by surrounding them with pillows to make their bed snug.



- Tape your own voice - tape yourself reading several of your child's favourite stories, they could listen to your voice after you had left the bedroom.
- Nap time - Keep any naps during the day short and not too near bedtime. It should become part of a routine and as early in the afternoon as possible.
- Rock it – children enjoy the rocking sensations to help them sleep – can you introduce this before bed.
- Create a sensory sleep space - Star struck - Stick dozens of fluorescent stars and moons on child's ceiling, and when the lights were off, the whole room was aglow. Colours - Try painting the bedroom in calming colours. Blues and greens are known to be great colours for relaxation. Studies show that blue is the best colour for sleep, as it induces sleep-time hormones. Black-out blinds - We found using black-out blinds in Sophie's bedroom made her sleep much better, especially in summer.
- Temperature control - Check bedroom temperature. 65 to 70 Fahrenheit / 18 – 20 Celsius is considered normal and check for drafts.
- Love my room - Don't use the bedroom as a place for punishment. You only want to have positive feeling associated with the bedroom.
- Massage - For relaxation try a foot, hand, scalp or body massage (use baby oils), it's very soothing and relaxing and great before bedtime. You can experiment with different pressures depending on sensory needs.





Mini landscapes on trays

Tactile play using trays and bowls, indoor and outdoor materials, water and favourite toys to hide and find within your 'tray landscapes'. Add colouring to water e.g. paint or build snowy environments using foam!

These can be accessed on the floor, table or placed on wheelchair or specialist seating/standing frame tray as part of fine motor and bilateral (two hands) sensory motor play.

Add plastic creatures or people if you like to make your own mini world or dolls party.



Flour fidget balls



You will need

- at least 2 standard size balloons
- Spoon
- Flour
- Water bottle with end cut off
- Scissors

Instructions:

- Put the small end of the 'funnel' into a balloon.
- With the spoon put flour into the funnel.
- Use the small dowel or straw to help push the flour into the balloon.
- Continue doing so until the balloon is about half full.
- Pinch the top (don't take funnel out yet) and shake the flour down. The flour needs to settle and compact within the balloon. You may also want to tap the balloon against your hand to help.
- Continue filling the balloon in this manner until you have compacted the flour down in the balloon and it is full to the neck.
- Take the funnel out and carefully squeeze out the air of the balloon. Be careful of flour dusting that may come out. Tie off the top of the balloon.
- Take another balloon and cut off the neck. Stretch this balloon over the one with the flour starting with the tied off end first. This helps to strengthen the balloon.
- If wanted, you can do this one more time with another balloon. Try using different materials such as playdough, flour with a little water, salt, or rice. Each will give a different pliability and tactile experience.



Sensory Bags

These sensory bags made using gel are wonderful for using our senses of touch and sight and combine especially well with the sunshine. Here's how to make sensory bags and ideas for using them for sensory play activities.



What you will need

- You need just two basic ingredients for your sensory bags: a strong, clear, plastic food bag, and some hair gel.
- Your bag needs to be strong enough to withstand handling by your child, so make sure you use something substantial. You can double up, with one bag inside another, and you can add extra tape around all four sides to secure it.

How to make a sensory bag

- Fill the bag with some of the hair gel. You don't need very much gel, just enough so it can spread it out in a thin layer and fill the bag.
- The gel-filled bag alone is great for sensory play, as it has an interesting texture for your child to explore, but there are many other ingredients you can include to offer different sensory experiences.
- Maybe add in some glitter, foil shapes (hearts or stars), buttons, pasta shapes, rice, cut drinking straws, googly eyes, foam sheets cut into shapes, letters or numbers, pom poms, lentils – whatever you find!
- How to play with a sensory bag
- Tape the bags down onto a table, or the tray of a wheelchair and invite your child to explore
- Tape the bags to a window and watch how the sun shines through!





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Light box

A traditional light box is used with children to explore objects with the added dimension of upward facing light, and can be brilliant for investigating silhouettes, colour mixing, x-rays and patterns, amongst many other things

To make our light box:

- Use a large, opaque, under-bed storage tub
- 2 strings of Christmas lights
- Large sheets of transparent paper (tracing or baking paper)
- Sticky tape

To assemble:

- Line the inside of the box lid with the sheets of paper and stick down with sticky tape. This will dull the light and help it to be dispersed more evenly.
- Put the Christmas lights into the box and spread them out evenly. Let the leads come out at one corner and the lid still fit over the top without a problem. If that doesn't work for you, simply make a small hole in the corner of the box and thread the leads through.
- Put the lid on, turn the lights on, turn off the lights in the room and PLAY!!
- Place the lightbox in a DEN!!!





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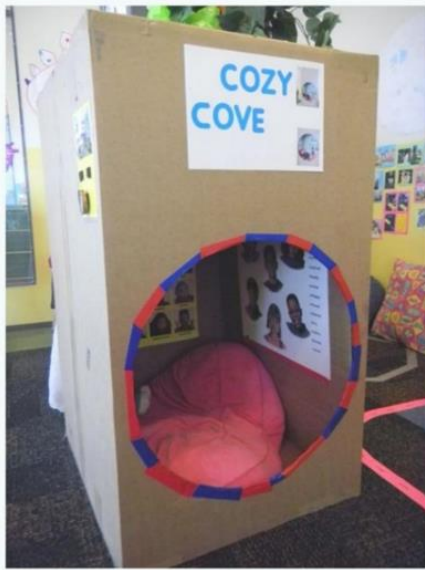


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Create a cosy den to play or self-regulate/snuggle in!

If you have any spare boxes or firm cardboard to tape together.... cut a hole in the side to climb in, but ensure you cover the edges with tape to stop any scrapes from rough edges. Put cushions and blankets in the bottom and decorate the walls! The den can be used as a new area to play with toys, indoors or out.

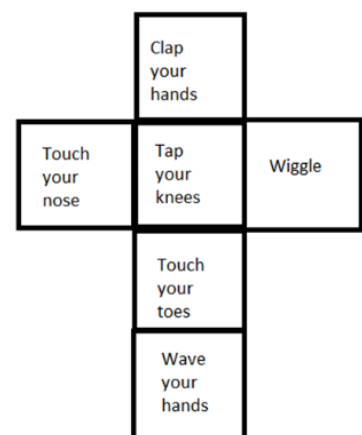
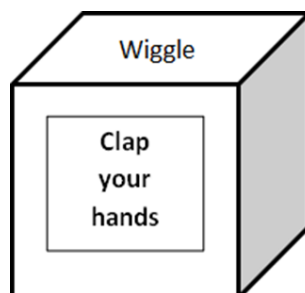
If your child has difficulty regulating sensory stimuli and/or needs time out somewhere more chilled this may be particularly useful. Having a darkened space can help a child self-calm/regulate within a space that is less stimulating or filled with items they find calming e.g. hanging mobile, some battery-operated fairy lights. Or make a den from blankets, chair, table.



Dice games

Dice games can be created for lots of fun. An example could be body awareness as pictured in the dice:

- Dice can be made from paper/cardboard. Like the template below.
- This game focuses on the child rolling the dice by encouraging a full grasp to letting go to roll.
- The activities can be as imaginative depending on your child's capabilities. Encouraging use of the non-dominant hand to roll the dice.





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Fun 'Gross Motor' activity

Great for developing gross motor actions, grasp and release skills

Sticky Spider Web

- Using some painter's tape (which doesn't damage paintwork) or masking tape create a spider web effect in a doorway or on a hoop- which can then be transported.
- Roll up pieces of newspaper/cotton wool/material or packaging, then AIM AND THROW! See how many 'flies' you can get on the sticky side of the web.
- If you attach tape to a hoop, it can be moved to help your child get a fly on the spiders' web. Maybe make some spiders or flies out of bits of wool or material!



STICKY SPIDER WEB

gross motor activity



Fine motor activities for a child with increased Upper limb/hand muscle tone

A child with hypertonia can have excess muscle tone in their upper limb(s) and hands that can lead to difficulties carrying out activities that demand fine motor skills. They may have problems grasping or releasing objects, isolating finger movements, varying their grip (pincer, tripod, span), turning their hand over (palm up) and adjusting elbow and wrist position to reach for items or to grade movements during activities.

The following exercises and activities have been gathered from parents and occupational therapists to help develop more typical patterns of movement, toward activity participation at home or school, as relevant to the child's developmental stage.

Preparation of upper limbs and hands through weight bearing and sensory motor activities that promote the use of both hands.

Weight bearing provides sensory-motor input toward 'proprioceptive feedback'. This is sensory information received into the muscles and joints that helps to reinforce body position in space and body awareness. Weight bearing increases sensory information through limbs, can help relax increased muscle tone in readiness to play!

Bilateral (two hands) upper limb (arms) weight bearing activities can be carried out in prone or face down. Wheelbarrow walking is great for weight bearing (see below)



- Other prone activities may include supported positioning over a wedge/roll, cushions or gym ball.
- Pushing activities also stimulate proprioception such pushing a laundry basket with two hands on the floor (fill with books to create weight, cover with a blanket and then put doll/toys inside).



- Pushing/pulling games e.g. palm to palm/into a soft ball or cushions, into the floor if side sitting or 'singing games' such as Row the Boat.
- Bilateral activities where one hand stabilises and the other plays e.g. waving bubbles, a flag, musical instruments or reaches to grasp something or hi-five!

Not a lot of children tolerate direct handling to an affected or tighter side, so you need to be creative and fun. Weight bear on the more affected hand while the child actively uses the less affected hand and swop. You may also want to consider a neoprene splint if the child mostly rests their hand in a fist position. Using the splint, weight bear in the desired position e.g. arm straight/finger straight.

- To encourage active reaching (anti-gravity) with the 'tighter arm/hand', position the child so the involved side is close enough to e.g. activate a toy through light touch/reach a touch lamp etc.
- Bilateral and unilateral reaching in different planes (horizontal or vertical) in a variety of positions (side or other sitting position) works on lengthening the affected side.



Sensory Activities to increase sensation to the upper limb and hand

- Use squishy balls or toys to squeeze that require gripping in 2 hands. In terms of grasp, try and stabilise the arm as much as possible when grasping e.g. rest forearm on the table initially, a cut out table/tray on chair
- Pull apart play-doh sausage, large cylindrical interlocking plastic blocks or beads (resistance=proprioception)
- Firmly holding paper down with more affected hand when drawing, finger painting



- Try to incorporate these activities before everyday play and/or self-care routines.
- Weight bearing through palms onto materials that offer sensory feedback e.g. textured/corrugated cardboard; wallpaper; fabric; containers/trays holding rice or sand.
- Reaching into or playing in rice, sand, different textures – bury toys or treasures in it.
- Trays holding wet or sticky materials to explore or paint or mix using tools with one or both hands
- Refrigerated or warm cookie dough, play-doh, pizza doh etc is wonderful to roll, squeeze or stretch with both hands or to find hidden toys/objects as part of learning while developing dexterity and strength
- Indoor bean sandbox. Take a shoebox sized tub and fill it with all kinds of raw beans, pasta, macaroni noodles etc. Use it to explore grasping or visual motor integration to locate objects or tool use.

In the kitchen/mealtimes

- Mixing bowl – cradling with non-affected upper limb and stirring or trailing fingers with affected arm.
- Picking up and passing veggies ready for peeling or practicing shopping soft fruits –
Don't forget hygiene and safety!





Activities to encourage wrist extension

- Activities against gravity encourage wrist extension and a tripod grasp. Your child may want to do this with or without wrist support or neoprene extension splint (if one has been issued).
- Finger painting on an easel
- Shaving cream on the wall of the bathtub/on a mirror
- Sticking things to a surface – placing on and pulling off with affected hand
- Leaning into the wall with the affected hand while painting a
- Picture on paper stuck to the wall/chalk board..
- Play dough activities, pretend cooking (flipping pancakes) and the shaker bottles with corn syrup and glitter, plastic confetti, etc. (can make your own with water bottle or small plastic bottle).
- Toys with the keys you turn, toy oven knobs etc. (also for neutral wrist; pronation and supination)
- Playing waiter (holding a tray and carrying it).

Finger Extension activities

- Preparation - opening of fingers – this links to weight bearing activities or manual stretching/massaging e.g. before play. Hand-washing is a good place to begin. Handling by using your thumb in the palm to push from middle and out toward and up each finger and thumb – this will provide a stretch.
- To extend fingers to open or release the grasp – pushing round objects into the palm and underside of knuckles, eg a ball, playdoh, roller (smooth or textured toy) and rolling out and up fingers.
- Animal walking and crawling – make a jungle out of sheets! Crawl up and over cushions/soft mats/beanbags – jumble them up and hide toys underneath
- Hand prints and painting
- Clapping and pushing games

Activities to encourage and develop a pincer grasp

- Picking rolled up paper, tissue, non chokeable objects out of an egg carton, small container
- Water bottle fun. Picking up small items such as plastic flowers, glitter, beads etc to fill a clear plastic bottle and adding coloured/clear liquid. If you are concerned about the child opening it, you can tape the lid on. This is visually appealing and may encourage bilateral hands to shake the bottle.
- Place stickers on the non-affected hand/arm. This way the child has to use the affected hand to remove the sticker using a pincer grasp.



- Tissue paper scrunching is a good exercise. The child crumples up bits of soft paper and throws them/drops them into containers. If mobile thrown around the room to then collect.

Activities to encourage supination (turning the palm up)

- Turning pages of a book
- “Guess which hand” something is hidden in one hand, the hider turns both palms up and opens her hands to show if guesser is correct.
- A simple “slinky toy” is a great toy to encourage Supination.
- Grasping a large magnet and holding it under paper/card to pull along an object or toy – may be draw and follow a path.
- Scooping up sand or water and pouring into another container, or sand / water wheel toy. Making sandcastles.
- Snack time, scooping and eating pudding! Eating in general
- Placing stickers, stamps on the opposite inner arm – turn to look at it.
- Playing with money and reaching for change
- ‘Give me five’; round and round the garden etc
- Grasping cups in palm with palm up and filling them with varying items.
- A small tambourine or other handheld percussion are great to use for supination / pronation because it is so visual.

While we can play outdoors and experiment with sports!



Please see: <http://www.dlf.org.uk/factsheets/leisure>

Other Resources

Newlife offers the free loan of specialist toys to families who have disabled and terminally ill children. The Play Therapy Pods are self-contained and are delivered direct to the family's door. Calling the free Helpline phone number 0800 902 0095 (free from UK mobiles & landlines) or by email <https://newlifecharity.co.uk/docs/care-services/Play-Therapy-Pods.shtml>

