

Supporting the family during Coronavirus lockdown

Neil Williamson Children's epilepsy nurse specialist

Topics to talk about today

- Coronavirus (COVID 19 update)
 - Current government advice what should all people be doing
 - What should families with a vulnerable person be doing
 - What are the true vulnerabilities in this situation.
- Life in lockdown Issues to consider
 - Family mental wellbeing Everyone having some head space
 - Risk assessments
 - Sibling support Young Carers to the MAX
 - Care packages and guidance
 - Respite



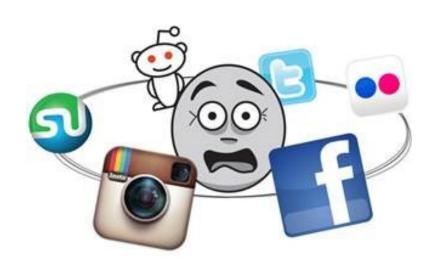
Coronavirus update – 15/04/2020

STAY HOME NIH'S STAY SAFE

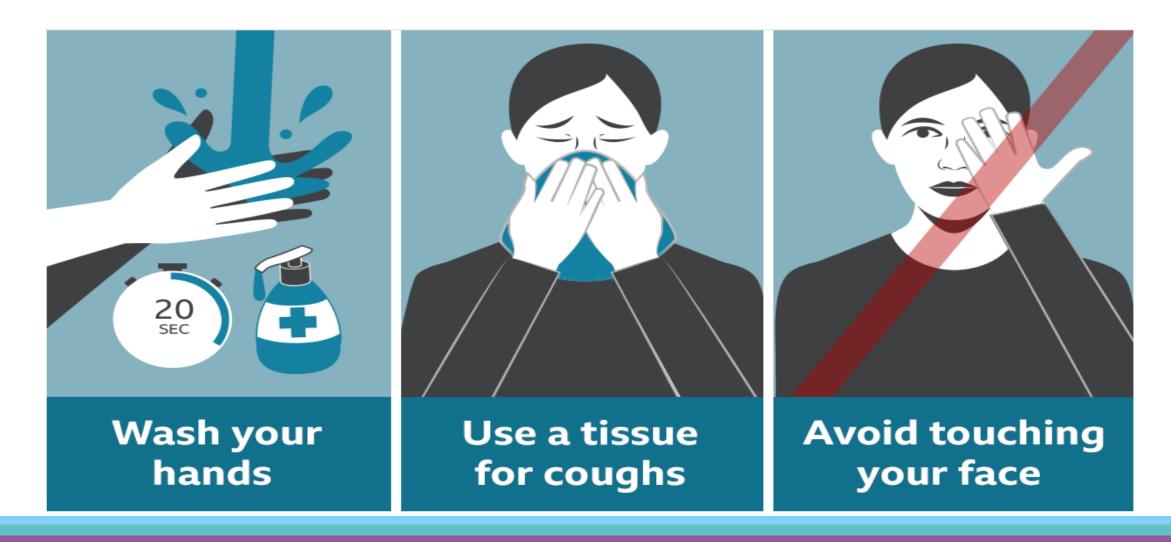
- All individuals in the UK should be -
 - Only leaving the home for keywork duties
 - Only shopping once a week if at all, collecting medications or going to routine health appointments
 - Daily exercise this can be in your own family group and during this you should stay a minimum of 2 metres from people outside your family group. This should be local to your home.
 - Dravet syndrome relevant issues -
 - There is a lot of discussion about face mask usage and I believe in people with a learning disability and young children that a mask can be counter productive.
 - Social distancing is hard for a person who does not understand the situation of COVID-19.

Social Pressures

- This pandemic has heightened our social awareness of what others are doing:
 - We now perceive we are thought of negatively if we get too close to people
 - Or leave the home too often
 - Lots of social media discussions with opinions and judgements easily made of how people behave
 - As a family with unique members within sometimes the rules cant necessarily apply to you

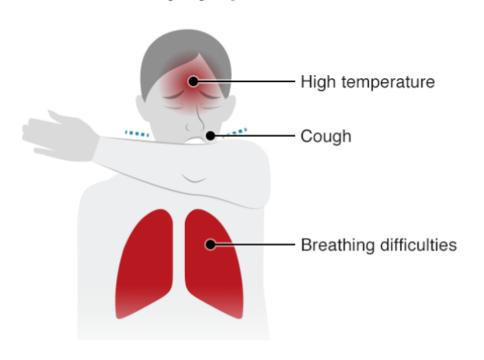


Key parts of protecting yourself



Knowing the symptoms - Isolation

Coronavirus: Key symptoms



- If a person has a high fever and/or a non productive cough then that person should isolate at home for 7 days.
- Anyone in the household should then isolate for 14 days to allow an incubation period then 7 days for the illness itself.

Who is a vulnerable person in this Pandemic – The key here is chest health and mobility

People over 70.

(ie anyone instructed to get a flu jab as an adult each year on medical grounds):

- •chronic (long-term) respiratory diseases, such as <u>asthma</u>, <u>chronic obstructive pulmonary disease (COPD)</u>,
- •chronic heart disease, such as heart failure
- chronic kidney disease
- •chronic liver disease, such as hepatitis
- •chronic neurological conditions, such as <u>Parkinson's disease</u>, <u>motor neurone disease</u>, <u>multiple sclerosis</u> (MS),
- a learning disability or cerebral palsy
- •diabetes
- •problems with your spleen for example, sickle cell disease or if you have had your spleen removed
- •a weakened immune system as the result of conditions such as <u>HIV and AIDS</u>, or medicines such as <u>steroid tablets</u> or <u>chemotherapy</u>
- •being seriously overweight (a body mass index (BMI) of 40 or above)
- •those who are pregnant

Isolation Vs A bit of time in the community

- The goal of the strategy of the UK government is to reduce transmission of the virus –
- When a person leaves their home they create a double risk
 - Getting the Virus
 - Giving the Virus
- Therefore a common sense approach having a person with Dravet syndrome in your family is needed: -
- Mental health of the family deteriorating because of strictly staying indoors
 is a big problem and it is essential to go out regularly following guidelines.
- Suspending care support and respite when this is the norm can be a big factor to family functioning.
- A child's behaviour who is not able to leave the home may deteriorate. It may improve.
- Domestic violence and abuse will increase across the country and disabled children are the most vulnerable group.
- Thinking about siblings as young carers and their burden.



Family mental wellness

- It is essential that all family members find new coping mechanisms
- This will all be about balance so set expectations within the family – everyone needs to be able to release some pressure everyday.
- Be aware of the potentially increased intake of food (chocolate), alcohol, screen time (though definitely needed) and how to balance that.



Family mental wellness (2) resources

- Parenting support https://www.unicef.org/coronavirus/covid-19-parenting-tips
 - Advice sheets for parenting advice https://www.unicef.org/media/67211/file
- Podcast for COVID-19 and people with autism https://www.acamh.org/podcasts/cornavirus-autism-a-parents-guide/
- Young people mental wellness course https://www.llttfyp.com/corona/
- Think Ninja –Anxiety support for young people 10-18 https://www.healios.org.uk/services/thinkninja1
- Parents toolkit managing stress https://www.psychologytoday.com/us/blog/pulling-through/202004/the-pandemic-toolkit-parents-need

Risk assessing the choice to leave home

- So keeping social isolation and lockdown always in your mind each day ask yourself what does the family need today – What is the impact of that decision – is it worth it for what the benefit will be.
 - One of the issues we have seen in paediatrics has been parents bringing their children to the hospital less and in cases this has actually been positive for families and the health service, it has however led to incidents of very sick children attending A+E – The best advice is to agree the plan going forward of when to attend and stick with it.
 - Other peoples behaviour You cannot control other peoples behaviour so try to choose outdoor activities where you know you can have space and where temptations to your child or family member will not be too great ie next to play park.



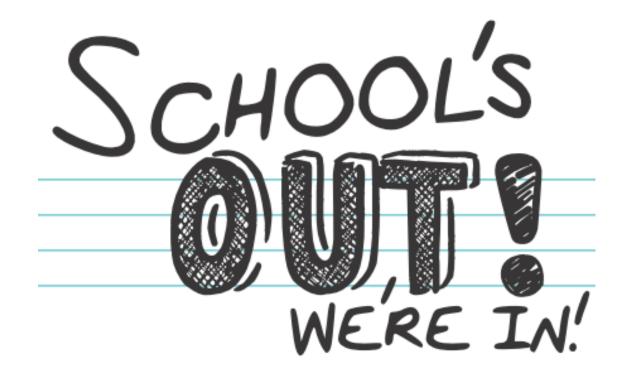
Sibling Support – We need them they need us

- Siblings will be invaluable in supporting this period of the pandemic lockdown however we need to be very aware of their needs and some of the issues facing them.
- Giving time when needed and space when needed.
- Knowing you will not get this right even if you do.
- Beware the extremely eager sibling this is probably a marathon not a sprint so try to ensure they do not burn out.
- Try to have 1-2-1 special time with all children in the day even if only for 10 minutes each day



School – Schools out for summer (or is it?)

- The rules around schools and nurseries is: There is provision for your child if you are:
- A keyworker and/or
- Have a vulnerable child and/or
- Have a child with an EHCP
- I am sure most people would have spoken with school but you can check with the local authority.



Carers

- The government has provided guidance on carers entering the home this guidance sets out the following scenarios:
 - The person being cared for has suspected or confirmed COVID-19
 - A person in the home has suspected or confirmed COVID-19
 - No one has suspected COVID-19
 - Waste management
 - Carer management of clothing
 - https://www.gov.uk/government/publications/covid-19-residential-caresupported-living-and-home-care-guidance/covid-19-guidance-onhome-care-provision
 - Carers if continuing work should be extra protective of the social isolation steps and act as a vulnerable person to reduce transmission risk.



Respite

- If the respite provision is still available as with risk assessing you need to decide if the risk is worth the benefit considering all family members and speaking with the respite provision regarding their steps to reduce risk of transmission.
- Be aware of the potential to self isolate on your family members return as a precaution in case they come in contact with someone with active COVID-19 so prepare food stocks, medications etc.



Resources around Coronavirus pandemic

- https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/ file/876715/Coronavirus_COVID-19_advice_on_staying_at_home_20200328.pdf - Easy read staying at home guide (graphical)
- https://www.childrenscommissioner.gov.uk/coronavirus/resources/ Resources for children at home
- https://www.commonsensemedia.org/resources-for-families-during-the-coronavirus-pandemic resources for family's – common sense media
- https://www.autism.org.uk/services/helplines/coronavirus/resources/helpful-resources.aspx -National Autisitic society – Coronavirus support.
- https://childmind.org/article/supporting-children-with-autism-during-the-coronavirus-outbreak/ Advice from the child mind institute
- <u>https://www.challengingbehaviour.org.uk/information/covid19information.html</u> Challenging behaviour foundation resources.

Disability grants

- https://www.disability-grants.org/ a list of multiple grants to access.
- https://reactcharity.org/ grants up to £500 for most things
- https://www.moneyadviceservice.org.uk/en/articles/charitable-grants-for-ill-or-disabled-people Grants for disability
- <u>https://www.familyfund.org.uk/</u> Family fund



