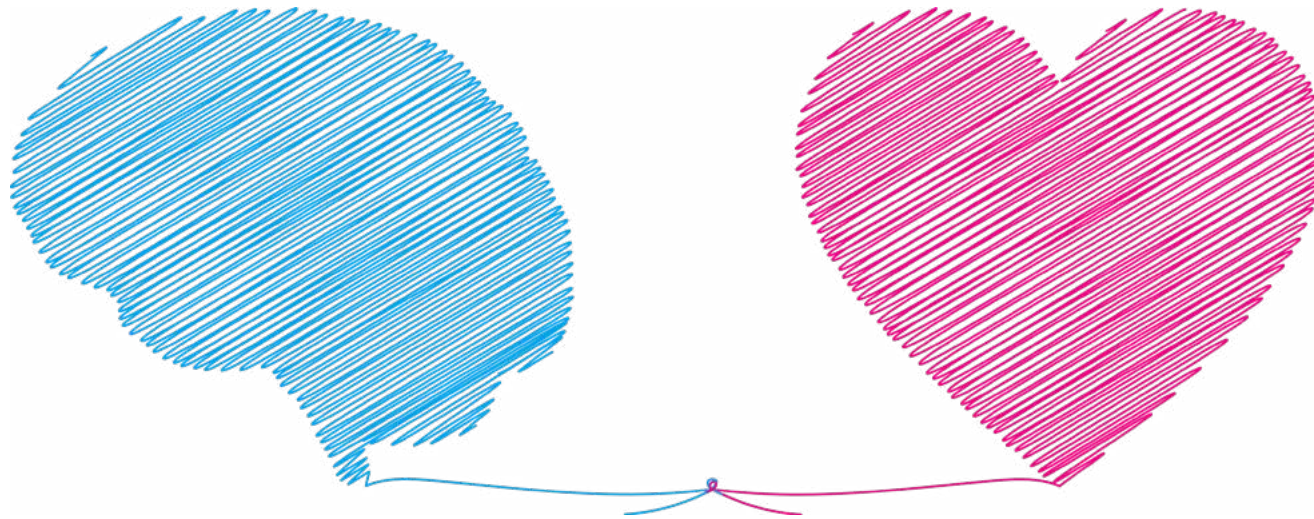


The Body & Mind Toolkit for Adults & Children

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An online information booklet with links to Wellness and Sleep, Eat Well and Move Your Body More resources in the COVID-19 Wave 2 pandemic period for people who use Highly Specialised Services and their families

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Disclaimer: Care should be taken when using these tools and resources as individuals may have specific health needs relating to their condition. Clinical advice from your specialist team should always be sought before use/if in any doubt. All tools and resources have been submitted in good faith.

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Glossary

Most of the tools in this toolkit apply to people of all ages.

Each of the three Themes contains online links to information leaflets, videos and other information that have already been made available to the people using these services by the NHS service listed or by the Charities and stakeholder groups which support them. Some of them have sent you personal messages which are shown in speech bubbles. Sincere thanks are extended to all who have made these contributions.

We hope that people of all ages who use these services and their families find these tools useful during the months of the COVID-19 Wave 2 Pandemic period ahead and help you prepare for the spring of 2021.



We hope you find our 'caring for yourself' tips useful. Best wishes from Kay, Anne & Emma (A-T Society)

"Please do not worry alone, no question is ever too small or trivial. We are here to help, so do not ever hesitate to contact us at NTUK" Karen, Charity Director, Nerve Tumours UK



Children's Liver Disease Foundation

fighting childhood liver disease

We are happy for people to call us on 0121 212 3839, Harpreet, Children's Liver Disease Foundation

NERVE TUMOURS UK

There are so many useful resources throughout this document... let us know what works for you so we can learn from each other and improve our health and well-being together... Best wishes, Tonia & Team BBS UK!

Wellness & Sleep



Ataxia Telangiectasia



The AT Society

We developed a 'Coronavirus' update page early in the pandemic. Here we try to simplify the info provided by the UK Govt and devolved nations – includes written text and videos of Kay and I chatting to everyone:

<https://www.atsociety.org.uk/living-with-at/covid-19-virus-coronavirus/>

'Caring for yourself' website page: with a growing body of content/resources for people to tap into to help self-manage emotional health and wellbeing. Includes stories from adults living with AT, resources from a range of topics such as home education, entertainment and exercises/relaxation information:

<https://www.atsociety.org.uk/living-with-at/covid-19-virus-coronavirus/>

See here for the main information leaflet

<http://www.alstrom.org.uk/family-support/#Comprehensive-Support-Guide>

Alström Syndrome Service

(All Ages)



Alström Syndrome UK (ASUK) is a charity who provide information, support and advice for individuals affected, their families and carers and professionals. Alström Syndrome is a very rare genetic condition which can cause progressive blindness, loss of hearing and can lead to; heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different stages making diagnosis very difficult. Our mission is to raise awareness, conduct pioneering research and enable better treatments and monitoring through the AS multi-disciplinary NHS clinics.

Further information about our work can be found at www.alstrom.org.uk

Contact Information:

Email: Catherine.lewis@alstrom.org.uk

Tel: 07970 071675



Mind - Mind offer support and information including useful guides on support and services available, you can view these here - <https://www.mind.org.uk/information-support/guides-to-support-and-services/>



The charity **Young Minds** offer support and information for young people experiencing mental health challenges and their parents. They offer guides around support which can be found here as well as a beginner's guide to the NHS's Child and Adolescent Mental Health Services (CAMHS) for young people and parents, this guide can be viewed her -

<https://youngminds.org.uk/find-help/your-guide-to-support/guide-to-camhs/>

Preparing for Adulthood – Provides resources and information for young people who are affected by disabilities as they move into adulthood. They offer specific expertise and support with paid employment, good health, independent living options and friends, relationships and community inclusion - <http://www.preparingforadulthood.org.uk/>

Covid 19 Mutual Aid UK

This a group of volunteers supporting local community groups organising mutual aid throughout the Covid-19 outbreak in the UK. They focus on providing resources and connecting people to their nearest local groups, willing volunteers and those in need. You can find out where your nearest local group is by visiting their website -

<https://covidmutualaid.org/>

Discover a World Online - Maybe you are looking for some culture, something a bit different to do. Now you can visit a museum or art gallery without even leaving the comfort of your couch.

The British Museum, London - Go to the link to find virtual tours, which are audio described too click [HERE](#)
Buckingham Palace, London - Go to the link to find virtual tours [HERE](#)

Guggenheim Museum, New York - Google's Street View feature lets visitors tour the Guggenheim's famous spiral staircase without ever leaving home. From there, you can discover incredible works of art from the Impressionist, Post-Impressionist, Modern and Contemporary eras.

Musée d'Orsay, Paris - You can take a virtual tour through this art gallery to discover many famous French artists, click [HERE](#) to discover more.

Van Gogh Museum, Amsterdam - You can virtually visit this museum by clicking [HERE](#) and discover the largest collection of artworks by Vincent van Gogh, including over 200 paintings, 500 drawings, and over 750 personal letters.

Vatican Museums, Rome - Welcome to the Vatican museums, the gardens, villas and surrounding area, with these 360 virtual tours you feel like you are there, discover all [HERE](#)

Natural History Museum, London - Discover the wonder of nature at the Natural History Museum, click [HERE](#) to enter the museum and discover fun facts, tours and activities.

For children Home Learning

Free home learning resources for all ages of children <https://allinonehomeschool.com/>

Cool Maths

If your little ones, love their numbers then why not head across to Cool Maths 4 Kids where lots of fun activities will keep your genius's entertained. <https://www.coolmath4kids.com/>

The Maths Factor - Learn maths with Carol Vorderman, her website services are now free!

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

National Geographic for Kids

This website provides lots of creative activities, competitions and fun facts for all ages to have a go at.

<https://www.natgeokids.com/uk/>

Twinkl as lots of educational activities for all ages and also some sensory stories and resources.

<https://www.twinkl.co.uk>

Fun Science and Technology - Science Kids brings an online resource of science activities, including games, quizzes, videos, cool facts and lots more to keep your budding scientists entertained. <http://www.sciencekids.co.nz/>

Here's some jokes to keep you giggling

'Why do tigers have stripes? So they don't get spotted.'

'What do astronauts do when they get angry? Blast off!'

'What do you call two dinosaurs that have been in an accident? Tyrannosaurus wrecks'

Dekko Comics

To help with home learning Dekko comics are offering their fun and educational comics free online. They offer over 140 comics to help with maths, english, science, history, geography and PSHE.

<https://dekkocomics.com/issue-list-home>

About COVID-19

How do I know the information is reliable?

There is a huge amount of information about Coronavirus and what we should all be doing to stay healthy during this pandemic. How do you know the information you are reading is reliable.

There are 4 sources of information which we use to gain the latest information and guidance. These are:

The Government website which can be viewed [HERE](#)

The BBC News website which can be viewed [HERE](#)

The NHS website which can be viewed [HERE](#)

Public Health England website which can be viewed [HERE](#)

Bardet-Biedl Syndrome Service (All Ages)



Staying mentally well during Covid:

<https://bbsuk.org.uk/coronavirus-information/emotional-well-being/>

Bladder Exstrophy Service (Children)

Some great resources here to manage thoughts around coronavirus

Coronavirus resource pack for parents <https://nhsforthvalley.com/wp-content/uploads/2020/04/COVID-19-Resource-pack-For-Parents.pdf>

Resource pack - Its ok to worry about coronavirus: <https://nhsforthvalley.com/wp-content/uploads/2020/04/COVID-19-Resource-Pack-Unders-Its-ok-to-worry-about-coronavirus.pdf>

Managing coronavirus related anxiety <https://education.gov.scot/media/2pdfjp5q/covid-19-resource-pack-overs-its-ok-to-worry-about-coronavirus.pdf>

The following links are for a PDF and video by Russ Harris with FACE covid strategies might be helpful for parents/older teenagers, and clinicians working with them. He is one of the leading experts in Acceptance and Commitment Therapy (ACT) <https://www.actmindfully.com.au/wp-content/uploads/2020/03/FACE-COVID-eBook-by-Russ-Harris-March-2020.pdf>
<https://www.youtube.com/watch?v=BmvNCdpHUYM>

Complex Congenital Osteogenesis Imperfecta (Children)



<https://brittlebone.org/support/general-support/>
(dates on our next independent living workshop – will happen after our Halloween party)

<https://brittlebone.org/support/information-resources/>
(please note the GYM fact sheet is being worked on at the moment)

https://brittlebone.org/support/information_and_resources/pilates-exercise-videos/
<https://brittlebone.org/update-on-covid19/>

Complex Neurofibromatosis Type 1 & Neurofibromatosis Type 2



The Nerve Tumours UK Helpline (Mon/Wed 9am-5pm 07939 046030) is run by a network of Specialist Neurofibromatosis Nurses and for patients with Neurofibromatosis Type 1, Neurofibromatosis Type 2 and Schwannomatosis and is available via email, text and phone.

It is totally confidential, and anonymous if required - <https://nervetumours.org.uk/help/line>

Nerve Tumours UK supports people with these conditions to live their fullest life, helping them to navigate the obstacles that Neurofibromatosis can throw in their way and can help with:

- Medical support
 - Are you seeing the right people, and getting all the information and treatment you need?
 - Mental health
 - You may have mental health issues you need support on, but are unsure what help there is and where you can access it.
 - Financial support
 - Are you getting all the welfare benefits you're entitled to?
Are there other possible sources of financial support?
- We can guide you and advocate for you on these and other issues.

Mental Health Support - <https://nervetumours.org.uk/help/general-mental-health-support>

Mindfulness & Pain Management -

<https://nervetumours.org.uk/help/mindfulness-support-and-pain-management-apps-and-resources>

Helpful Charities - <https://nervetumours.org.uk/news/helpful-charities>



The charity provides internal forums on its social media channels where people with the condition, parents or carers can freely speak with peers and others affected with similar issues related to Neurofibromatosis.

<https://nervetumours.org.uk/help/social-media-support>

The iNForm Program supports people from the point of diagnosis through education, and into employment

<https://nervetumours.org.uk/help/inform>

iNForm your GP about Neurofibromatosis

https://nervetumours.org.uk/images/downloads/NTUK_INFORM_GP_Letter_2020.pdf

Support throughout the current crisis <https://nervetumours.org.uk/help/neurofibromatosis-covid-19-coronavirus>

Online Meetings specifically for those with hearing impairment increases its importance due to the pandemic

<https://nervetumours.org.uk/news/accessible-online-meetings-for-those-with-hearing-impairment>

Multiple Sclerosis Management Service (Children)



Sleep tips -

www.evelinalondon.nhs.uk/resources/our-services/hospital/sleep-medicine-department/covid19-sleep-tips.pdf

See the MS Trust's Youtube channel MSTV which has content on wellbeing, mental health and exercise, with more coming later this year. www.youtube.com/c/MSTVUK/videos



Primary Ciliary Dyskinesia Management Service (Children)



See the British Lung Foundation webpage on singing:

www.blf.org.uk/support-for-you/singing-for-lung-health/improve-your-wellbeing

Specialist Liver Disease Service (Children)

Blogs - Please note some of these articles reference financial support and links to guidance from the first lockdown which may not be applicable in the second wave. The blogs may provide practical advice, signposting and tips for emotional wellbeing and mental health.



Try to do something that matters to you each day, and I hope these resources offer some ideas along the way.

Ruth, Consultant Clinical Psychologist
Manchester Bladder Exstrophy service

Your family's emotional wellbeing and mental health blog (Published April 9, 2020): <https://childliverdisease.org/your-familys-emotional-wellbeing-and-mental-health-published-april-9-2020/>

Navigating a New World for Young People (Published March 25, 2020): <https://childliverdisease.org/navigating-a-new-world-for-young-people/>

Coming out of lockdown – how do we integrate back into a new world (Published July 3, 2020): <https://childliverdisease.org/coming-out-of-lockdown-how-do-we-integrate-back-into-a-new-world/>

Information: The Non-Alcoholic Fatty Liver Disease leaflet has tips and advice around reducing the risks of NAFLD, diet, exercise activity and lifestyle for children.

<https://childliverdisease.org/liver-information/childhood-liver-conditions/non-alcoholic-fatty-liver-disease/>

Wolfram Syndrome Service (All Ages)



WOLFRAM SYNDROME UK

Shared information for our community which includes recordings of webinars with clinical leads of the NHS service

<http://wolframsyndrome.co.uk/covid-19-news/>

Also see <http://wolframsyndrome.co.uk/wp-content/uploads/2020/11/Wolfram-wellbeing-pack-mental-wellbeing-V3.pdf>

Alström Syndrome Service (All Ages)



Alström Syndrome UK (ASUK)

Webinar links can be found in our resources section, which include information about a range of topics including healthy hearts.

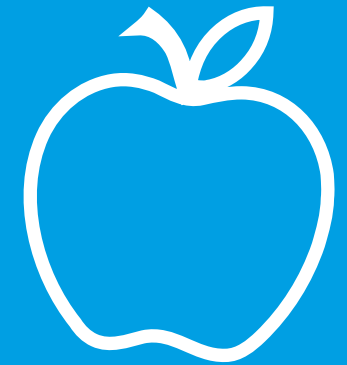
<http://www.alstrom.org.uk/family-support/>

Healthy recipes, including top tips on nutrition which have been created by the service Dietitian can be found on the 'Stay Fit, Stay Healthy, Stay Happy' section of the website: <https://www.alstrom.org.uk/stay-fit-stay-healthy-stay-happy/>

A Children in Need funded cookbook is in development for Alstrom patients to include equipment and health and wellbeing top tips with support from the Physiotherapist, Dietitian and Psychologist. An online version will be free to use.

The NHS has advice and guidance on their 'Live Well' website - www.nhs.uk/live-well/

Eat Well



Primary Ciliary Dyskinesia Management Service (Children)



See links to the British Lung Foundation Stay active and stay well pages with lots of exercise videos www.blf.org.uk/support-for-you/keep-active/exercise-video

See British Lung Foundation Eating Well pages www.blf.org.uk/search/site/eating%2owell

Specialist Liver Disease Service (Children)



Non-Alcoholic Fatty Liver Disease (NAFLD): this leaflet has tips and advice around reducing the risks of NAFLD, diet, exercise activity and lifestyle for children. It also provides links to lots of resources available with ideas for being healthier, easy recipes and meal ideas as well as ideas for getting active (page 14):

<https://childliverdisease.org/liver-information/childhood-liver-conditions/non-alcoholic-fatty-liver-disease/>

Wolfram Syndrome Service (All Ages)



Shared information for our community which includes recordings of webinars with clinical leads of the NHS service

<http://wolframsyndrome.co.uk/covid-19-news/>

Contact:
admin@wolframsyndrome.co.uk

“I’m happy that we have been able to continue to support our community through these difficult times and found new ways to communicate with members new and old. We have managed to support those who were reluctant or found it difficult to participate before now by using new communication methods which has made it easier to join in.”
Tracy, Wolfram Syndrome UK

Move Your Body More



Alström Syndrome Service (All Ages)



Alström Syndrome UK (ASUK)

Website - there are health and wellbeing resources for families and case studies showing how families have adapted to exercising from home. These links also contain short films from families and professionals.

As well as summaries from the Health and Wellbeing webinars we have organised throughout the pandemic, including a range of topics for example Managing Diabetes at Home.

<https://www.alstrom.org.uk/stay-fit-stay-healthy-stay-happy/>

<http://www.alstrom.org.uk/family-support/>

The 'Alstrom Stroove' is in development. This is music with a set of generic stretching exercises which have been developed alongside the service's physiotherapist. Due to lock-down filming has had to be postponed, but you can see a sneak, peek of the moves on our website. We are working with schools and families to see if they can film sections and we can edit into an exercise video to inspire others exercise.

www.alstrom.org.uk/groove-to-the-alstrom-stroove-sneak-peek/

Bardet-Biedl Syndrome Service (All Ages)



Summer newsletter article which formed the basis for a diet/health/wellbeing resources section on our website: <https://bbsuk.org.uk/diet-and-exercise/>

Home workouts

<https://www.facebook.com/546759972144864/videos/3067775939951251>

<https://www.facebook.com/546759972144864/videos/882274765518476>

via the 2.4 challenge which some patient and family members of the Charity got involved with and they found that the community aspect was really important and helped offset the isolation of COVID-19 a little.

Complex Congenital Osteogenesis Imperfecta (Children)



<https://brittlebone.org/support/information-resources/>

(please note the GYM fact sheet is draft and being worked on)

Pilates exercise video

https://brittlebone.org/support/information_and_resources/pilates-exercise-videos/

Multiple Sclerosis Management Service (Children)



See the MS Trust's Youtube channel MSTV which has content on exercise, with more coming later this year. <https://www.youtube.com/c/MSTVUK/videos>

“Facing a pandemic when you have a long-term health condition can be daunting. For young people with MS, we’ve dedicated a Youtube channel called MSTV to all aspects of living with MS, including films on wellbeing and mental health that can apply to all of us, any time. Here’s the link: <https://www.youtube.com/c/MSTVUK/videos>

We hope you find something useful here. If you have any queries about MS, you can email the MS Trust Enquiry Service at ask@mstrust.org.uk and we can give you honest, evidence based information to help you reach your own decisions about MS.”

Primary Ciliary Dyskinesia Management Service (Children)

See links to the British Lung Foundation Stay active and stay well pages with lots of exercise videos <https://www.blf.org.uk/support-for-you/keep-active/exercise-video>



Specialist Liver Disease Service (Children)



Our Non-Alcoholic Fatty Liver Disease (NAFLD) leaflet provides links to lots of resources available with ideas for being healthier, easy recipes and meal ideas as well as ideas for getting active (see page 14)

<https://childliverdisease.org/liver-information/childhood-liver-conditions/non-alcoholic-fatty-liver-disease/>

Blogs - Please note some of these articles have reference to financial support available during the first lockdown which may not be applicable in the second wave.

A section in this blog provide links and advice about simple exercises that can be done at home - <https://childliverdisease.org/coping-with-a-new-normal-for-families/>

Wolfram Syndrome Service (All Ages)



Shared information for our community which includes recordings of webinars with clinical leads of the NHS service

<http://wolframsyndrome.co.uk/covid-19-news/>

Glossary and list of Charities and stakeholder groups in this edition with main weblinks

The AT Society	The Ataxia Telangiectasia Society	http://www.atsociety.org.uk
ASUK	Alström Syndrome UK	https://www.alstrom.org.uk/
BBSUK	Bardet Biedl Society UK	www.bbsuk.org.uk
Brittle Bone Society	Brittle Bone Society	https://brittlebone.org/
Children's Liver Disease Foundation	Children's Liver Disease Foundation	https://childliverdisease.org/
The MS Trust	The Multiple Sclerosis Trust	www.mstrust.org.uk
Nerve Tumours UK	T/A The Neurofibromatosis Association	https://nervetumours.org.uk/
PCD Family support Association	PCD Family support Association	https://pcdsupport.org.uk/
WSUK	Wolfram Syndrome UK	https://wolframsyndrome.co.uk/