

**Family Webinar 16th April 2020
Life in isolation, healthy mind and body**

Chaired by Marie McGee, ASUK National Transition Coordinator and Ann Chivers, ASUK Chief Executive

Thank you to the families who sent in questions and queries. We hope these answers and top tips will help in this uncertain time.

Supported by professionals from Birmingham Women’s and Children’s Hospital (BWCH) and the ASUK Family Support Team.

* Catarina Leal, BWCH Dietitian
* Jemma Mears, BWCH Physiotherapist
* Sarah Turner, BWCH Psychologist
* Carrol Birchall, ASUK Family Support Worker (FSW)
* Jane Biglin, ASUK Family Support Worker (FSW)

**Q1.**
**We try and eat healthy, but we find that everyone is eating more snacks and eating at different times - What tips do you have to help with this?**

Catarina gives her top tips:

* Keep busy
* Keep to a routine
* Family choose the snacks for the day and add to a packed lunch/basket
* Healthy snacks include, cucumber and carrot sticks, fruit and yogurt, nuts, low-fat crisps such as quavers
* Recommend that everyone should be taking a 10mg of vitamin D per day. Our main source of Vitamin D is from the sunlight, we can’t get enough from our diet and this helps with calcium absorption and supporting our immune system.

**Q2.
Do you have any suggestions for healthy, simple meals with ingredients that are easy to get?**

Catarina gives her top tips:

* Look for balanced meals with a range of fruit and vegetables and oily fish
* Tinned and frozen fruit and vegetables contain just as many vitamins and minerals as fresh
* Hearty balanced meals such as hot pots, stews, soups, lentil Bolognese, home-made pizzas using pitta breads, flat breads and wraps as the base.

**Q3.
I am not very motivated to exercise, how can I motivate myself?**

Jemma gives her top tips:

* Important to remember to do what is comfortable for you, especially when following online videos and apps
* Important to set goals daily so we all have something to work towards or even try competitions as a family
* Equipment such as the swiss bouncy ball or using what you have at home, such as doing step-ups on the bottom step of your stairs

**Q4.**
**I know there are lots of suggestions of how to exercise on YouTube/internet it’s a bit overwhelming which one to do. Can you suggest any exercise that people with Alström could do? Also, what are the best exercise sites or apps to use….?**
Jemma gives her top tips:

* There are lots of apps and exercise routines online to follow, it’s best to explore these and see what works best for you
* Do what is comfortable for you, within your own limitations
* Chair activities are good and keeping things slow and simple to start with and then build upon these as you get more confident
* Find apps and exercise routines which describe what they are doing, and basic techniques such as balancing
* Resources covering different exercise routines and apps can be found on the ASUK website <http://www.alstrom.org.uk/family-support/>

**Q5.**
**I am not sure how to organise for my medication to be ordered online or how to organise for it to be delivered to my home.**

Carrol gives her top tips:

* Due to the restrictions you will be unable to go into your GP practice to order your prescription as usual.
* These are now done through an app which sends your prescription from your GP to your chosen pharmacy
* Check if your chosen pharmacy delivers by giving them a call or ask a friend if they can collect for you and deliver to you
* You may need to contact local pharmacies to see who is delivering, if this is easier than it being collected for you

**Q6.**
**My days seem to be endless; I don't really have a routine for myself and my family, how can I change this?**

Sarah gives her top tips:

* Routine is very important
* Evidence shows the less routine we have in our lives, the less we do, the less motivated we feel and the more tired we feel, which becomes a vicious cycle
* Get a planner, to plan your day together, looking first as what you need to do and then add in the fun things you would like to do, keep it balanced with a mixture of necessity and fun such as connecting with family and friends on facetime
* Draw support from your loved ones and share how you are feeling with them
* Ask Alexa or google assist to remind you of your routine throughout the day
* The more you schedule, the more you will do, but also remember to be flexible and kind to yourself if you aren’t feeling up to doing everything that day.

**Q7.
I am worried about lots of things, my future, what’s happening with the virus, all sorts of things. I use social media and listen to the news this makes me scared, but I also like to know what’s going on, how can I stop being so worried!**

Sarah gives her top tips

* It is normal to feel worried and anxious now as there are lots of uncertainties
* Using a worry box may help, jot down the worry and add to the box, which is in a different room, try and let it go, it can also be done on your phone using your note-taker
* Set aside time to worry so it doesn’t affect your day to day
* Share with a loved one or imagine what you would say if a friend had those worries
* Make sure you use 1 or 2 reputable news sources
* Try and limit to watching the news only once or twice a week and turn off notifications
* Use a worry doll or safe space such as a den
* Remember it is OK to feel angry and frustrated, be kind to yourself

**Q8.**
**I have not received a letter from NHS to say I am in the extremely vulnerable group, this is causing me problems with shopping, what can I do about this?**
Jane and Carrol give their top tips:

* All families with AS have now received an NHS letter from QE or BWCH
* The central register is now being updated with all people affected by AS
* Supermarkets should then get in touch with a link to your regular priority slots
* For some this register is still being updated with their details and many are using Covid-19 Mutual Aid who are volunteers working locally in your area to help
* Register on the gov.uk website
* Slightly different if you reside in Wales or Scotland but links are available to register in the same way
* Get in touch with your ASUK FSW if you still haven’t had any contact or need support with registering

**Inspirational stories**

‘Hammer Down Hassan’ [**https://www.alstrom.org.uk/hammer-down/**](https://www.alstrom.org.uk/hammer-down/)
Showing us all how it is done with his exercise video
Why not share your videos and photos of yourself exercising to inspire others?

**Families join in to share their top tips:**

* Audio stories and the Living Painting tactile books are fantastic
* Joe Wicks exercise routine every morning, is a good start to the day and can be adapted so everyone can join in no matter what their ability
* Practical skills and independent skills are good to develop currently, such as making a hot drink and simple cooking
* Read together and use the time to develop Braille skills
* Enjoy tactile games together
* Make the most of the sunshine if you have a garden or outside space
* Try not to compare yourself to what others are doing
* Enjoy time together

**Top Tips from the webinar:**

* Keep to a routine
* Find exercises that suit you and build upon these
* Express your emotions
* Remember it is OK to feel angry and frustrated, be kind to yourself
* Take time to relax
* Look at self-help guides
* Keep connected to friends and family
* Get in touch with your FSW if you need support
* Enjoy this time together and have fun together!
* Check out the useful resources on the ASUK website [**http://www.alstrom.org.uk/family-support/**](http://www.alstrom.org.uk/family-support/)

**Thank you to all the professionals who gave their time and guidance in this webinar and for the families who joined in with their top tips.**

**Stay Home. Stay Safe. Stay Well**