



4th November 2020

Hello everyone,

We hope you are well.

We wanted to produce a statement ahead of the second national lockdown which goes into effect on Thursday 5th November 2020.

The government's guidelines have not changed much for those for who have been previously categorised as being "clinically extremely vulnerable".

The Prime Minister announced there is no shielding this time around but has advised those who are most vulnerable to take extra care and avoid or limit contact with others as much as possible. You can still go out for recreational purposes but please be vigilant and ensure you are following hand hygiene and infection prevention guidelines.

We would advise all our members with thalassaemia to be extra cautious.

Your life matters and we want you to stay as healthy as possible.

Please follow the government's guidelines here:

<https://www.gov.uk/guidance/new-national-restrictions-from-5-november>

Please find the updated guidelines for the National Haemoglobinopathy Panel here:

<https://static1.squarespace.com/static/5e8ca9bcda00561f349fa870/t/5f9a89c10acba321a760e141/1603963332900/COVID-19+advice+update+October+2020.pdf>

Please get in touch with your thalassaemia team if you are concerned or worried about how this new lockdown may change your service.

Psychological Well-being

We know how difficult this time is for everyone and the thought of a second lock down can result in feelings of anxiety or cause low moods. We understand this and share in your frustrations. We are deeply concerned about the well-being of everyone with thalassaemia and their loved ones.

As a result, we have put together some top tips to help protect your psychological well-being during this period of uncertainty.

Now you may wonder, what is exactly is well-being.

Well-being is your own perception and evaluation of your life.

It is based on questions such as:

How you are thinking?

How you are feeling?

How do you perceive your interaction with others?

How you are you functioning overall?

It is entirely based on YOUR perception and no one else's!

The individual components of well-being stand for PERMA.

PERMA stands for:

Positive Emotions – which are things like optimism, love, laughter, - all these wonderful more subjected aspects of happiness and pleasure.

Engagement – being able to function in your life, slowing down and being present.

Relationships- loneliness is really closely linked to depression, have at least one person to connect with.

Meaning- serving something bigger than yourself- which gives you a purpose outside of your needs.

Accomplishment- pursuing goals, feelings of success and striving to accomplish something for yourself. This helps with believing in yourself.

These components of well-being represent different aspects of your life that you should pay attention to. The more you pay attention to them, the

more you will have well-being in your life. Far too often, we get consumed into concentrating on one aspect, but we need to focus on all areas to ensure we get the most out of our lives. If you are struggling in one component of PERMA, this can cause an imbalance in your psychological wellbeing.

Pre Covid 19 was a lot easier for us to maintain our well-being as we were able to interact face to face with others, to go on holidays, enjoy dancing the night away with friends or even taking a walk outside without feeling anxious if we came into contact anyone with the virus.

However, as the restrictions began reducing, we were able to interact more with others and resume some of our previous activities.

With the thought of a second lockdown in close proximity, we have heard from some people with thalassaemia have been feeling frustrated, angry, sad and concerned about how they are going to cope.

Despite lockdown preventing us from experiencing and implementing many of the wellbeing components in our lives in the ways we would usually prefer, there are ways in which we can adjust our coping strategies to ensure all aspects of our well-being are met.

We have created a well-being plan for you and your family!

Here are a few suggestions for building **positive emotions**:

- Start each day by planning 2-3 things you and your family are looking forward to doing- it is important to have a routine.
- Exercise daily- whether it is a walk to the park or even dancing.
- Watch funny or interesting tv shows, or movies, read books, do artwork, listen to music.
- Focus on nutrition and eat together as a family, where possible.
- Start a family gratitude jar and make it an essential part of your day where everyday people write something that went well or something, they are grateful for.

Here are a few suggestions for building **engagement**:

- Discover your / your family's creative side (artwork, music, cooking etc.)
- Try to limit your screen time- this can affect your sleeping patterns!

- Be curious- it's never too late to learn something new!
- Learn some mindfulness and relaxation techniques.
- Make time to have meaningful conversations with people who matter.

Relationships-Interactions with friends, family, colleagues, children and our community impact our wellbeing as we feel loved, supported and valued by others.

How do you maintain relationships in lockdown?

- Keep your support network strong, even when you're only able to call, text or contact friends and family on social media. There are many ways to have a virtual meeting, please continue to do this until it is safe to meet face to face!
- Start sending handwritten notes or messages to your family and friends- especially those who are isolating. It can be a form of comfort for them!
- Spend some 1-1 time with people in your household

Meaning – We need to feel like we belong and have a sense of purpose.

Having a reason to get out of bed each morning or experiencing a strong sense of belonging gives our lives meaning.

- Do something for someone else- even if it's just to check up on them daily or weekly to see how they are getting on
- Get involved with the UKTS- we always need your help on projects!!

Accomplishments – We need to believe we can improve our abilities and succeed.

Having a sense of accomplishment means working towards goals. This helps us to improve our abilities and our belief in ourselves.

- Set goals for yourself-whether it be through exercise, eating healthier, educating yourselves or even practicing self-love and self-care!

Exercise

Staying active during this period is beneficial for both your physical and mental health. Going on a walk/run outdoors for 20-30 minutes a day will give you a break from being inside, give you some fresh air and help you take in some vitamin D from the sun. Even if the weather is cold and rainy, there are lots of ways you can stay active inside, for instance you can do yoga, bodyweight workouts or put some music on and dance around your living room!

You might want to take this time to try out something new or set yourself a challenge! You can also do these workouts with your friends over facetime/skype where you can motivate and challenge each other!

Here are some links Yoga links provided by Shayla Ghelani you might like to try out!

1) Yoga for Health - Directional Movement of the Arms:

<https://www.youtube.com/watch?v=M9VSpOiwwDU>

2) Yoga for Success - Neck Practices:

<https://www.youtube.com/watch?v=JnhUmq0va4A>

3) Chit Shakti Meditation for Health:

<https://www.youtube.com/watch?v=RO7ysvrFsac&t=273s>

4) Yoga for Peace - Nadi Shuddhi

<https://www.youtube.com/watch?v=q5m6tMjcF8k&t=49s>

5) Yoga for Joy - Nada Yoga

<https://www.youtube.com/watch?v=Ug8OoFAFfZ0&t=285s>

6) Yoga for Love - Namaskar Process

<https://www.youtube.com/watch?v=lx6Zr6lrTal&t=17s>

Exercises for bone strength and density- there are lots of workout plans that you can try:

<https://www.nhs.uk/live-well/exercise/exercises-for-strong-bones/?tabname=fitness-guides>

Nutrition

Nutrition plays a role in strengthening the immune system. To ensure we have a balanced immune system, we need to be eating a balanced diet. A balanced diet essentially means eating foods from different food groups as each has its own health benefit. Follow the link below to access the Eatwell guide.

<https://www.gov.uk/government/publications/the-eatwell-guide>

A varied diet is important as obtaining the nutrients from your diet first is always best to get all the essential micronutrients. Some vitamins that are of importance for protection against infection include vitamins A, C, D, E, B2, B6, and B12, folic acid, iron, selenium, and zinc (3). A multivitamin (without iron) could be an option for you if you are struggling to meet the recommended vitamin requirement but be sure to check with your consultant before consumption.

Vitamin C contributes to immune defence as it supports our white blood cells and in turn, the process of removing harmful cells from our body (4). Vitamin C can be found in foods such as citrus fruits (oranges), vegetables such as peppers, tomatoes and fruit juice. However, it is important to note that when vitamin C is eaten alongside sources of iron, iron absorption is increased. **Therefore, it is important to be mindful of this and try to avoid eating foods that are high in iron with those that are high in vitamin C.**

Vitamin D promotes the body's absorption of calcium, which is essential for the maintenance and development of bones and teeth. People who are indoors shielding may not be getting enough exposure to sunlight and in turn may not be getting enough vitamin D. Although vitamin D can be obtained through the diet, sunlight is the main source. Therefore, it is recommended by Public Health England to take a daily vitamin D supplement containing 10mcg. Please check with your consultant before doing so! Studies have shown that maintaining your vitamin D status reduces the risk of respiratory tract infections (1,2). It is important to note

that this does not mean vitamin D will protect you from COVID-19 but that it may reduce the risk of infection.

Top tips

- Planning your meals ahead and writing a list of ideas for breakfast, lunch, dinner and snacks might help you feel less stressed about what you are going to cook. Now you have more time at home, it can be a fun way to spend time with your family and try out some homemade recipes. You can check out the UKTS website or our on social media to find some easy recipes: <https://ukts.org/treatment/nutrition/>
- Stay hydrated! Try to drink enough water and if you find it difficult to drink plain water, try adding squash, lemon or fresh mint to add some flavour.
- Have a nice warm cup of tea with your meals to reduce iron absorption!

Don't forget to treat yourself once in a while; we are in a pandemic after all! Remember to be kind to yourself!

It is never too late to start improving or working on ourselves!

If you do experience or develop any difficult thoughts or feelings during this lockdown, please contact your teams for support! Please don't suffer in silence, it is a challenging time and there is support!

If you feel as though you need more support, please contact your thalassaemia team or get in touch with us for non-medical issues.

Here are also some other charities that may be of help.

<https://ukts.org/>

<https://www.nationalhaempanel-nhs.net/>

<https://mentalhealth-uk.org/>

<https://www.mind.org.uk/>

<https://www.samaritans.org/>

We will continue to update you with our news so keep on the lookout!

Stay well and keep safe!

References

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3. Centers for Disease Control and Prevention. Keep children healthy during the COVID-19 outbreak. 2020. Available at: <https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/children.html>. Accessed 3rd November, 2020
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6. Seligman, M., (2018): PERMA and the building blocks of well-being, *The Journal of Positive Psychology*, DOI: 10.1080/17439760.2018.1437466