

**Autism Advice Live**

**Joanna Panese, Practice Development Manager**

**9 April 2020 at 8.30pm**

Question

**We are experiencing real difficulty at bedtime with our son. Unfortunately, we have had to resort to our son sleeping in our bed. Is there anything we can do to make bedtime easier? Before COVID-19 he settled very easy. He is 4 years old. Recently diagnosed in February.**

Answer

I can understand at this time this is such a challenging time to keep a sense of routine going, but first and foremost the advice I can give to you is be kind to yourself, everybody is going through a really stressful time at the moment and it’s important that families are able to take a break and be kind to each other during this time.

Advice around sleep can vary depending whether it is a child, adolescent or adult so if you are experiencing difficulties or issues around sleep with adolescents or adults then please do contact our Autism Advisors and they will be able to give more specific support than this that might be more around a young child such as this young lad. So the first thing you can do in this sort of circumstance is have look at the routine around going to bed. What does it look like? Is it possible to structure that routine a wee bit more as we’re building up to bedtime, that might be going for a nice warm bath or shower or snuggling down to read a favourite story or complete a favourite task something nice and quiet, maybe a jigsaw as well they are very good as well, very relaxing and nice quiet activities that you can do that just sort of signals that it’s time to settle down its time to get ready for bed. Try and do these things in the child’s bedroom so that they are familiar with that environment and that’s a comfortable and safe place for them.

It might be as well that he is experiencing a level of anxiety in relation to what’s going on. He might be worried for himself that he might become poorly or that mum or dad or any other member of the family might become poorly as well. What might that mean? Our children are listening to a lot of things that are going on through the news and things like that so it could be the possibility that he’s experiencing quite a level of anxiety around that. So it might be worth seeing whether or not you can talk to your child about what is happening and that will differ depending on how old your child is and what their preferred communication style with that. Just spend a few minutes reflecting on that day what were the positives of that day and making things nice and positive and nice and light but recognising as well that this is a huge change that’s happened in our children’s lives he may want to be closer to you and physically feel your presence and that might be what is happening here.

And as well I’m sure routines of family members at home have changed as well maybe Mum and Dad going out to work and now they are at home as well so everything is a bit different and that causes anxiety as well. Try to plan out what the day is going to look like and what are your plans for the day and what your expectations of him and what his expectations of you as well. Look at explaining what is going to happen in the day to your child so they get a bit more familiar to that change of routine that might help with him. Is it also possible to maybe try some more physical activity later on in the afternoon if you have a garden are you able to get out in the garden have a run around or can you take a walk around your neighbourhood in that late afternoon period it just helps to expand extend some of that energy as well if little one has been in the house all day as well it might be likely that he has energy to expand and needs to get rid of that so little bit of light exercise late afternoon and then start the bedtime routine from that point onwards might help settle back into that routine. Most importantly during this time it is about looking after one other and being kind to yourself if your little boy is in bed with you then this is nothing gone wrong it’s just what he needs at that time. Obviously it’s really important that you look after yourself in this too as well. We do have resources around managing your wellbeing if you have a child at home and you can find them on our [website](https://www.scottishautism.org/services-support/covid-19-support/wellbeing).

Question

**The lockdown advice seems vague and open to wide interpretation. I liked As I Am’s clarification to view outdoor exercise as no more than 40 minutes, for example, which is much clearer than “once a day.” The symptoms advice feels very hard to interpret for someone like me who tends to go quite some time before properly registering somethings wrong.**

Answer

The UK Government did publish some new guidance on this on 29 March which stated that a walk of up to one hour or a cycle or a run of up to 30 minutes was seen as a reasonable amount of exercise. Please remember this is once a day and within your local area please do not get in your car and drive to a place.

There was some clarification around individuals whose care plans state that they do require more outside space and they are able to do that but it must be very clearly stated in that individuals care plan that they need to take outside exercise more than once a day but there was new guidance that was released about that very recently.

This guidance is in place to prevent the spread if infection and to protect those communities around us and to protect our NHS so do be mindful that if you are going out wash your hands when you come back into your house and stay in your local area where you are going and only exercise with members of your household or your carer or person that is coming in to support you, that’s fine as well. You can go out with your carer even if they do not live in your household they have clarified the guidance on that too.

The second part of this gentleman’s question is around the symptoms advice and he said that he finds it very hard to interpret someone who like him tends to go for quite some time before recognising that there is something wrong potentially. This is a common issue that many people have that recognising when something is different. So what you could maybe do in this circumstance is to write down or to record what does well feel like for you on a normal day to day basis and then that might help you recognise when things are not the same as they usually are and then help recognise that you might have symptoms of something or a change somewhere. The guidance honestly is or the symptoms of Coronavirus are: A high fever of 37.8 or greater and a new and continuous cough, so it might be worth if you can getting hold of a thermometer or if you have a thermometer in your home that you can check your temperature and that will tell you whether or not you are experiencing a fever or whether or not you are just hot for other reasons. It can be worth having one of those in your home if you can get hold of one or ask someone to bring one for you. But as I say a new continuous cough or a high fever or high temperature. A new continuous cough we’ve had some people enquiring saying that’s quite a confusing statement in itself so the NHS Inform have produced some guidance to say what a continuous cough is so that is a new cough that lasts longer than an hour and you have 3 or more episodes of coughing in a 24 hour period that would be what would be termed as a continuous cough.

For further information relating to Coronavirus please visit our [website](https://www.scottishautism.org/services-support/covid-19-support/covid-19-coronavirus-information-resources).

Question

**Where can we get help with PIP form in times like this as my daughter is 16 this month? She’s on DLA at the moment she has a learning disability, epilepsy and autism.**

Answer

In usual circumstances there are lots of places where you can go to get face to face support to fill in forms such as this. Your local Citizen’s Advice Bureau they will offer you an appointment to bring your form in and work through it with them as do your local Carers Centre, however, obviously right now they are not able to do this face to face appointments however Citizens Advice have published lots and lots of supporting information on their website and again specifically for the PIP claims as well. They have a designated space on their website and they are providing telephone appointments as well to talk you through what is required in each section and likewise with the local Carers Centre. You can find details of your local Carers Centre at the Care Info Scotland website and they have a list of all the Carers Centres in Scotland and we will include links for this in the Resources list.

You mentioned in your question that your daughter has epilepsy, Epilepsy Scotland have Welfare Rights Officers that are able to help and guide you with benefits forms however we have been informed just recently that there is waiting list for support from them, however they are making every effort to work through that as quickly as possible but obviously recently there has been an increase in the amount of claims so they do have a waiting list however they are able to offer you that support, again it will be over the telephone.

The DWP also have advisors that would normally be able to support with this but as you can understand the DWP is experiencing a high level of enquiries and calls at the moment for benefits payments so your first port of call would probably be your Citizens Advice and your local Carers Centre.

Further information on the organisations mentioned above can be found on the Autism Advice Live section of the [website](https://www.scottishautism.org/services-support/covid-19-support/autism-advice-live).

Question

**I am looking to find out what support will be available to my son when he returns to school after being off for an extended period of time?**

Answer

This is a common question that we are being asked what support will be put in place to support children back into that school environment when they have been off for what will be quite a significant period of time. Now for some children with autism not being at school, not going into that social situation, not being in that environment will actually suit them really well being a bit more relaxed at home being able to access things on their own terms in a very familiar environment will be really beneficial for them, however, there will be other children who not having that routine and not having that sense of being able to go out to school can be quite difficult for them. We have lots of resources on our website about supporting home learning, about supporting your child and yourself in that situation when you are both at home.

With regards to planning for going back to school when the schools reopen then all schools will be asked to look at planning for that when it comes the time to reopen. Our advice would be to contact your school class teacher if you are able to or the support for learning team that have been around that child when the time comes to look at what plans might be put in place whether that be refamiliarisation being able to refamiliarise yourself with the environment, looking at more routines and just building in that very slowly into that child’s routine that they will be returning to school at this point, but as I say I would wait until you have a date of when the schools are going to reopen before maybe starting that process. Things like calendars to help mark the time off and give that concrete understanding of the passage of time can be hugely useful to explain this. There might also be some worries and anxiety about returning to school and what might that be like, what will this situation be so worry boxes where you can jot down what your worries are and pop them in there and bring them out to have a brief conversation with might be useful, social stories or visual supports that explain what is going on can also be useful in this time. We aim to ensure that those are bespoke and specific to individual children or people so if anybody would like more support in producing social stories or visual supports for their child then please do email into us and one of the advisors will get back to you and we will be able to offer much more individualised support around designing those type of things because it is important to get it right for that child and as I say there are lots of resources on our website that might be useful too.

Question

**Can I visit my autistic nephew who lives 6 miles away? Out with of current situation I would normally visit my nephew 2-3 times a week as a wellbeing check as he lives along, to provide shopping and to prepare meals.**

Answer

We had a look around the guidelines around this and NHS Inform came back and said that families and carers who are providing essential care can continue to visit the individuals that they are helping so you can still continue to visit your nephew if you are providing him with essential care so providing shopping, medication then yes you can still continue to do that. Also it might be worth talking through with your nephew what would be the contingency if you weren’t able to visit is there other things that you can do remotely digitally staying in touch there are lots of great apps around now or Facetime or a just a phone call to keep in touch wellbeing, are you able to batch cook meals that he can prepare himself that might reduce the amount of visits you are having to make. These are things that you can chat through with him about and find what suits him but as I said the NHS Inform guide is that families and carers providing essential care can continue to do this.

Question

**Can I accompany my autistic child into hospital if he were admitted?**

Answer

I would imagine this is probably a great source of worry to a lot of people who are worried if their autistic child or family member were to be admitted to hospital for whatever reason would somebody be able to be there to support them?

The Scottish Government have just recently updated the guidance around this so we can share that with you tonight, so obviously they are wanted to reduce the risk of spreading Coronavirus and obviously shield vulnerable groups so NHS Boards are being asked to restrict the amount of hospital visiting that is taking place to essential visits only but they have clarified that if you are visiting hospital to support someone with a mental health issue such as dementia, a learning disability or autism where not being present would cause the patient distress then you can continue to visit them. So if in the case of this question of your autistic child was admitted to hospital yes you will be able to go with him in line with this guidance here. Obviously any visitor to hospital should consider if their visit is essential in these cases. Just to recap anyone with a mental health condition such as dementia, or a learning disability or autism can have somebody with them if they need that person if not having that person would cause them significant distress.

Question

**Many autistic people experience anxiety and worry about communicating via phone, will there be scope for other forms of communication to be used?**

Answer

I think this question was submitted in relation to GP appointments and some other medical appointments being moved from face to face appointments onto telephone only appointments. Primary care providers are following Health Protection Scotland guidance which means that they have been asked to really significantly reduce the amount of face to face contact they are having and only seeing patients for essential appointments only. Some GP practices are able to offer video consultations, not all, but some individuals would need to highlight their needs to their GP practice themselves. You can ask an advocate or friend to support you to explain this to your GP or you can email your GP and explain to them how you would prefer to communicate with them is there another way of doing it and explore those options with that GP. As I say some GP’s are able to offer video consultations but not all so best to check with your local GP practice to find out how their approaching it. But as I say the best thing to do is to contact your specific GP about that.