



Swansea Parent Carer Forum

COVID-19

Information for Parent Carers

Issue 2 (22nd June 2020)

Co-produced with Swansea Council and
Swansea Bay University Health Board





Swansea Parent Carer Forum are a voluntary group of parent carers all with children with additional needs. We have co-produced with Swansea Bay University Health Board and Swansea Council, the most frequently asked questions by parent carers at this time. This document will be updated to keep the information as current as possible. It is really important to us that we hear about your experiences accessing services and that you let us know what questions need answering.

We refer to 'your child/children' throughout this document on the clear understanding that you may also be looking after an adult child. This information is for parent carers whatever the age of their child.

Health

I'm worried about going to the doctor's or hospital during this virus - what do you suggest?

It's really important that you still get medical help or advice for the same issues that you would have done before the coronavirus epidemic. Not doing so could put your health at risk. All GPs and hospitals have adapted their services to keep you and your family as safe as possible.

I'm worried about taking my child to hospital as they need me to support their behaviour and communication. Will I be allowed to stay with them?

We know many parents are worried about not being able to stay with their children if they take them in to hospital and there has been some reassuring official advice which we have set out:

On 20th April, Wales' Chief Nursing Officer said people who don't have COVID-19 would be allowed to visit patients in a number of circumstances including:

- One parent or guardian for paediatric inpatients and neonates.
- Someone with a mental health issue such as dementia, a learning disability or autism, where not being present would cause the patient/service user to be distressed.

Arrangements should be discussed and agreed with the relevant Ward Manager so that your family's circumstances can be taken into account.



You can also prepare for a hospital visit by creating a 'Hospital Passport'

My Hospital Passport gives children a voice when visiting hospital. My Health Passport is a way for children and young people with autism, learning disabilities or complex health needs to share important information about themselves when accessing care in hospital. My Health Passport is a simple but important document that will empower children and young people and their families to communicate their needs, wishes and values to those caring for them. Using Widgit symbols, the passport contains three sections; things you must know about me; things important to me; and my likes and dislikes.

Create your Hospital Passport

Are Child & Adolescent Mental Health Services (CAMHS) able to help my child at the moment?

Yes. CAMHS have adapted their service. Although routine face to face CAMHS outpatient clinic appointments have stopped, they are providing telephone consultations for advice, therapeutic support and medication monitoring. Face to face appointments are being offered on an individual basis as required to manage clinical need and risk.

They have a telephone service which is open for children, young people and their families for advice and support. It is open 9am-5pm, Monday to Friday. Please contact 01639 862744.

What's happening with assessments for ASD / ADHD?

Since 17th March, all face to face clinics were cancelled.

ASD appointments are continuing using video calls. Where possible, the Neurodevelopmental Disorders Team can offer assessments, but this may not always be practical. ADHD referrals are now starting using video calls.

If there are any queries, the team can be contacted on 01639 862459.

My child is awaiting surgery which we have been told will be happening soon. How will the pre-assessment happen in a safe way?

Non urgent paediatric surgery has restarted. There will be some face to face pre-assessments for children and 48-72 hours before surgery, children will be swabbed for COVID-19. This will be done face to face in a clinic setting with nurses wearing PPE and every effort will be made to make this as stress free as possible for your child.

We normally have therapy sessions at Hafan Y Mor. Are these services going to return to normal anytime soon?

The Physiotherapists and Occupational Therapists are now back in their normal posts. They are offering virtual appointments as well as triaging over the phone. Waiting rooms are being assessed and plans implemented to offer face to face appointments once it is safe to do so.

I've had some virtual hospital appointments for my child and they have worked brilliantly for us, totally cutting out the stress and anxiety that a trip to hospital usually brings! Will we be able to continue to have virtual appointments in the future?

We hope so! Welsh Government has recognised the many positives that have come out of adapting services to the current situation and have said newly introduced digital services are here to stay. Swansea Bay University Health Board had already been piloting the 'Attend Anywhere' service which offers virtual appointments and has brought forward its roll out during the current situation. You can find out more about it here:

Attend Anywhere Appointment

My child has been referred to see a Community Paediatrician but I haven't heard anything yet. Is this service seeing anyone?

At the moment, only urgent referrals assessed by a multi-disciplinary team are being seen by staff wearing full PPE. However, work is underway to re-open community and acute services. Community Paediatricians are also offering virtual clinic appointments where appropriate.

My child receives a nappy service from the Child Disability Health Team. They have grown and we now need a bigger size. Who do I contact to change the size?

The Child Disability Health Team can help you with this on 01639 862797. They also continue to assess new children for the nappy service over the phone or the new 'Attend Anywhere' virtual appointment service

I have regular deliveries of nappies for my child from the All Wales Delivery Service. I have lost the number to re-order and cannot contact anyone. Who can I ask for the number?

The number for the 'All Wales Delivery Service' is 0800 9883680. If you have any queries about nappies, then please contact the Child Disability Health Team on 01639 862797. e over the phone or the new 'Attend Anywhere' virtual appointment service

Early years

My child is under 5 and has Additional Learning Needs and I am a Keyworker. They are usually cared for by family members whilst I am at work, however this is not possible at the moment. Can my child access additional support if I need them to attend a childcare setting to enable me to work?

Yes. Swansea Family Information Service can provide you with information on the childcare settings that are operational. The childcare setting will be able to apply for additional funding to support your child's needs. Please contact them on 01792 517222 for further information.

I am feeling overwhelmed with trying to support my pre-school child's additional learning needs and need some support.

Who can I contact?

Swansea Children's Centre are offering support from one of their Early Years Additional Learning Needs specialists. You can contact them on 01792 572060 and a member of the team will call you back to discuss your worries and concerns. They will be able to offer you advice with supporting your child's needs as well as your own wellbeing.

I am worried about my child's speech and language development. Can I still access support?

Yes. The Speech and Language Therapy Team are continuing to provide support. Please contact them on 01792 517863. You will receive a call back where advice can be given and further support identified where needed. The Early Years Team have also produced some advice on how to support your child's speech and language development.

[Click here for support](#)

My child's community paediatrician had intended to refer them for a Statutory Assessment of their Additional Learning Needs before they start school. This has not happened and they are due to start school in September. What can I do next?

You should contact your community paediatrician through The Children's Development Centre (Hafan Y Mor) on 01792 200400.

My child is due to start Nursery / Reception in September and I am worried about this transition. How can I make sure their needs are met at school?

Your child's school should be in touch with you in the near future to plan for this. Primary Schools are working hard with the Educational Psychologists to develop transition pathways for young children with Additional Learning Needs who are due to start in Nursery or Reception in September.

I have an older child with Additional Learning Needs and I am worried about the development of their younger sibling. What should I do?

Contact your GP or Health Visitor in the normal way who are still able to refer to supporting services. Children's clinics are able to offer virtual appointments where appropriate. You may also wish to contact the Children's Centre on 01792 572060 where you can discuss any concerns.

I have a young child with additional needs whose behaviours have become more challenging since lockdown is there anyone who can help?

Lockdown is very challenging for families and some children in particular. You can get support from the Child Disability Health Team by contacting 01639 862797. They normally run behaviour workshops for families and continue to provide support as normal, albeit remotely.

Your Children's Centre will also be able to support you with behaviour and they can be contacted on 01792 572060.

Early Help Hubs (previously Team Around the Family, Family Partnership Team and Evolve) can also provide you with advice and support can be contacted on 01792 635400 or earlyhelphubs@swansea.gov.uk.

This website is also helpful for advice and support in this area:

[Click here for support](#)

We are desperate to use the fabulous Sensory Room at the Children's Centre. Is there any chance of it opening soon?

The Children's Centres are working hard to work out a safe way that this room can be used again and they will keep us posted.

As schools are opening in June, I was wondering if my Flying Start centre will be opening as well?

Flying Start Centres will be working with their associated schools to provide some childcare from June 29th and providing this as safely as possible. Your Flying Start Manager will be in touch to discuss this with you. Staff will continue to keep in touch as they have been doing. If you are not sure if there is a Flying Start in your area, then contact the Family Information Service on 01792 517222 who will be able to help you.

I thought it might be a good time to try toileting my child, but I don't know where to start as he/she has developmental delay.

It could be a great time to try out toilet training. Contact the Child Disability Health Team who normally run toileting workshops. They will work with you remotely through some tried and tested strategies. Contact them on 01639 862797.

Child Services

I've just found out about Carer's Needs Assessments and I think I need one. Is it possible to get one during this time?

Carer's Needs Assessments are still taking place using virtual technologies as it is not possible to meet face to face yet. If your child does have a social worker, please give them a ring to arrange a Carer's Needs Assessment. Social workers can be contacted on 01792 635180.

If your child does not have a social worker, then contact the Child and Family Information, Advice and Assistance Service. We recommend emailing them access.information@swansea.gov.uk as their contact telephone number is experiencing high call volumes. However, if you are unable to email or if your call is urgent, then please contact them on 01792 635700 and wait on the line.

To find out what might be involved in a Carer's Needs Assessment take a look at this guide to getting an assessment by Carers Wales:

Carers Wales Factsheet

Our circumstances have changed and I really think my child needs support from social services. Is this possible?

Absolutely, it is business as usual in Child Services and children's assessments are still



continuing. If you already have a social worker assigned to you, then please give them a ring on 01792 635180. If you don't have a social worker then we recommend emailing the Child and Family Information, Advice and Assistance Service at access.information@swansea.gov.uk as their contact telephone number is experiencing high call volumes. However, if you are unable to email or if your call is urgent, then please contact them on 01792 635700 and wait on the line.

Each week gets harder and harder. My child's meltdowns and aggression are getting worse and I'm feeling really unwell due to the stress. We are all physically and mentally drained. Can I get any help?

The Child Disability Team have already been able to support families whose needs have increased during the current situation.

Please contact your social worker on 01792 635180 to discuss what support can be provided.

If you do not have a social worker, please contact the Information, Advice and Assistance Team on 01792 635700 or access.information@swansea.gov.uk

If your child is of school age, then you can also speak to your school who can work with you and help you get the support you need. Schools are able to refer to the Early Help Hubs (previously Team Around the Family, Family Partnership Team and Evolve) as well as specialists in behaviour and additional needs.

You can directly contact Early Help Hubs on 01792 635400 or earlyhelphubs@swansea.gov.uk who can offer support from birth to 18.

This website is also helpful for advice and support in this area:

[Click here for support](#)

Earlier in the year my child was awarded direct payments but I have heard nothing further. What should I do?

If there is a delay with the introduction of a service or direct payments, please contact your social worker straight away. If your child is under 18 then you can contact their social worker on 01792 635180. If they are over 18 please contact 01792 614100. One of the responsibilities of your

social worker is to work with other professionals to help ensure your child receives the care and support they need. This includes working to resolve any practical issues you may be experiencing.

Adult Services

My adult son/daughter's day provision is now closed and they have moved some of their services online. Can I still continue to use my Direct Payments to access them?

Yes. If you think the adapted service can still support your child, then confirm with your social worker.

Will I still be charged for local authority day services if they are closed?

No, all charges for day and respite services have been suspended during this time. If you are continuing to receive bills, then please contact your social worker to discuss them.

I am really struggling to support my adult child. I am desperate for a break, what can be done?

Some emergency respite and day support could be available so please contact your social worker to discuss if this would be appropriate or if there is other support that can be put in place.

We have non-agency carers coming to the house and we can't get hold of any PPE to protect them and ourselves.

Swansea Council can provide all direct payment recipients with required PPE by contacting 01792 636445 or DPsupport@swansea.gov.uk. If you are able to source your own PPE you can purchase them using your direct payments fund.

I am really worried that my adult child's support will be reduced if we are seen to be coping. Might this happen?

No, your ability to cope during the pandemic will not influence decisions made about your ability to cope in normal times. The LA is aware many families are supporting individuals to keep them safe in this extraordinary time and acknowledge that this is not sustainable in the long term.

We normally have an annual health review with our GP. My son's review normally takes place in July but I'm not sure if they are happening anymore.

This service was suspended on the 17th March 2020 along with other enhanced GP services. Welsh Government has advised GPs of a phased approach to reintroducing this service between 1st July 2020 and 1st October 2020. The advice is to use telephone or video consultation and to use face to face appointments only when necessary. Contact your GP to find out when they plan to resume their annual reviews for Learning Disabilities.

When are day services and respite going to open?

Day services remain closed and there is limited respite and day support available. Many staff are still redeployed elsewhere. These services however are carefully planning, in accordance with Welsh Government guidance, how and when these services may open.

My son/daughter has reached adulthood and we are supposed to be looking at their next steps. What support is there as we move to these new services and can some of this be done virtually as we are very anxious that we are well prepared?

The usual transition sessions haven't been able to take place whilst services have been restricted. These sessions are really important to prepare young adults for this next important step and planning is taking place to create alternative transition material such as videos to help young adults begin to prepare.

I've seen other services offering opportunities online instead? Are services run by the local authority going to offer something online instead?

Some online and remote activities are happening with some of the LA run services and they are looking at creating a menu of what is available. Contact the service you currently use to find out what support they are able to offer.

We are aware of the following for adults with additional needs that are being offered remotely:

Friends of Fforestfach WDS have a weekly evening quiz on Tuesdays, please check out their Facebook page:

Friends of Fforestfach WDS

CanDo Hub have moved their services online and are providing their existing clients with online Zoom sessions in fitness and basic skills. There is also a daily Makaton supported activity, ranging from exercise, dance or songs open to all on their Facebook page. These sessions run Monday to Saturday at 13:30. There is also an open dance fitness Zoom class on Mondays.

Check out their Facebook page:

CanDo Hub UK

Shine Cymru Life Skills Centre continue to support their clients online. Check out their YouTube Channel:

Shine Cymru Life Skills

Your Voice Advocacy are providing activity packs for their members (membership is free) via the post or anyone can have one via email. They also offer competitions and challenges on their social media pages.

They hold at least two Zoom meetings a week, on a Tuesday and Thursday at 1400. Tuesday's session is more arts and craft, whilst Thursday is more topical chats and advocacy based. Other Zoom meetings have included a karaoke session and they hope to start Bingo in early July.

They also have some 'friend' volunteers who are willing to phone and chat with people on a regular basis.

Contact Sandi on sandimitchell@yourvoiceadvocacy.org.uk to find out more.

Education

The announcement on the return to school on the 29th June, whilst exciting for some, is a particularly anxious time for families whose children had complex needs. There is no pressure for children to return to school and families are being encouraged to do what is right for them. We recommend discussing any concerns with your school. Many schools are creating videos and booklets to support the transition back to the new school environment. Schools are not providing school meals and are asking families to send in a packed lunch if necessary.

Swansea Council have prepared a list of frequently asked questions which they are updating regularly:

Frequently Asked Questions

They have also created transition guides for both pupils and parents which you might find useful:

[Guide for Parents](#)

[Guide for Pupils](#)



I'm not sending my child back in June, will there still be support for their education?

Yes, your school will continue to support your child with their education.

Will staff or children be wearing PPE in schools?

In most circumstances teachers and support staff will not wear PPE. To keep children and staff safe schools are implementing social distancing and hand hygiene procedures which are the most effective measures.

Where social distancing cannot be achieved such as in cases where there is a need for physical support & personal care or to receive first aid, then staff may wear PPE to protect the child and themselves. Children may be discouraged from wearing face masks as Welsh government advises that if they are not able to wear them effectively, they could put themselves at increased risk of infection. If you have particular concerns around the use of PPE then please contact your school to discuss them.

We rely on school transport. I have a child who goes to an STF on the other side of Swansea, a child in our local primary that is too young to walk alone and their sibling is in Comp which has no safe walking access. Without school transport how can my children go to school now and in the future, they are all desperate to return?

As you can imagine, organising transport under social distancing rules is extremely complex. The number of pupils that will be able to travel at any one time is significantly reduced due to social distancing. For example, on a 49-seater coach, 12 pupils will be able to travel and only 1-2 in a large taxi or a 16 seater mini bus.

Schools will be asking you to transport your child to and from school if possible. If you are unable to do this and your child is usually entitled to transport, schools should ensure that this continues to be offered. If there are issues with providing the transport entitlement, then Swansea Council may offer you a petrol allowance but this would be on a case by case basis.

If you need transport to get your child to school, please let your school know that you will be returning to school and you definitely need transport.



My school has told me the nursery is not opening in June. My daughter with additional needs is due to start Reception in September and I am worried about her going back after such a long time away from school. What do you suggest?

Schools will be producing lots of materials to support the transition back to school in September like videos and booklets. Contact your school to discuss your child's particular needs, especially if they will require an OT assessment or special equipment.

My child wasn't eligible for FSM but our circumstances have changed. Am I now able to apply for FSM?

Yes. The quickest, cheapest and easiest way to apply for free school meals is online:

[Apply for free meals](#)

More information about about free school meals and other ways to apply can be found here:

[Find out more](#)

We only have limited access to the internet via my phone and/or only one device between all the children. How can my child carry on learning / access what school are providing?

There is a Welsh Government programme to provide access to the internet for those families who do not have it. Please contact your school

for further information.

We are really struggling to cope at home. Can my child go into school?

Key workers and vulnerable learners can access childcare from school hubs if there is no safe alternative. Please contact your school or social worker to discuss if this is the right option for your family or if other support is available. School Hubs follow strict social distancing rules, children do not play together and staff are advised to maintain social distancing where possible.

We could do with some advice from a specialist teacher/ OT / Behaviour specialist.

Who can I contact?

The Council's Additional Learning Needs and Inclusion Team continue to support parent carers of learners during this time.

Schools are working hard to support children with additional learning needs and you should contact your child's school for advice and support.

Access to specialist support can be arranged via your school. If you need further advice, you can contact ALNU@swansea.gov.uk.

I and others think my child needs a Statement of Educational Need. We had started the process, but what is going on at the moment? Is the process continuing?

Yes. Currently there is no immediate change to what local authorities have to do. Your school should be able to give you an update on how your child's assessment is progressing, otherwise you can contact ALNU@swansea.gov.uk to get an update. You may also take the opportunity to discuss any particular needs that you have at this time.

I have an appeal in progress to the SENTW - will it still go ahead?

Yes. Appeals continue to be processed. The SENTW have asked that all correspondence including application forms and written submissions be sent to their email as they have very limited, or no access to items delivered by post. Their email address is Tribunal.Enquiries@gov.wales.

My child has additional needs and I am very concerned about the transition from primary to secondary school?

Swansea's secondary schools are working hard to prepare transition paths for Primary Year 6 pupils to prepare them for their new school when they enter Year 7. Your child will be contacted by their new schools with transition packs in the very near future, if they haven't already. Additional preparation for children with

ALN continues between the secondary schools ALNCOs and their primary school counterparts and you should receive information about this indue course.

We are getting work to do at home from school, but it hasn't been differentiated for my child's additional needs. What should I do?

Contact your class teacher or ALNCO at school. They should be able to provide work to do at home which is suitable for your child's need.

Parent carers

I'm having difficulty with managing my child's bedtime and sleep routine, he/she won't settle until very late and wakes during the night.

This can be an exhausting time for families. The Child Disability Health Team can help guide you through the steps they usually advise in their sleep workshops. They continue to work as per usual but remotely at this time. Contact them on 01639 862797.

As a parent carer, can I access PPE equipment?

Yes you can. The LA has made PPE available for unpaid carers and this is being managed by Swansea Carers Centre who can take you through the eligibility criteria such as COVID-19 symptoms. You can order two weeks supply at a time and Swansea Carers Centre will deliver this to you. Please contact Swansea Carers Centre to enquire on 01792 653344 or admin@swanseacarerscentre.org.

We have recently received a shielding letter. How can I get help?

Help and support is available from the Council for those who do not have friends, relatives, neighbours or voluntary organisations to assist them. This can be accessed by emailing at Covid19@Swansea.gov.uk or via the Council's helpline on 01792 636363.



My 12 year old daughter helps with the care of her sibling. I'm worried about her emotional wellbeing as she is not able to get much of a break due to the restrictions. Is there any support for her?

Yes. Swansea YMCA continues to provide support for young carers aged 8-18 across Swansea. They offer activities, assessments and a range of other support, including 1:1 and group support via a range of online platforms such as video conferencing. Please get in touch with Egija Cinvaska on 07946 348878 or egija@ymcaswansea.org.uk.

My child's DLA/PIP benefit is due to be reviewed. Where can I get help?

Swansea Carers Centre continues to offer support for ALL benefits; DLA, PIP, AA, UC, UC50, ESA50, Council Tax Reduction, Carers Allowance, Benefit checks and any benefit query you may have.

These forms are being completed over the phone, the benefit advisers can talk you through each question and answer. You can WhatsApp photos of evidence to them.

Please phone 07984 445493 / 07984 445491 and a telephone appointment will be booked for you.

I am worried about what will happen to my child if I become ill from COVID-19.

The risk of becoming seriously ill from COVID-19 is still very small.

It might be reassuring to know that if an emergency does happen, replacement care for your child will get sorted out quickly.

Carers UK have an excellent guide to creating an emergency plan for you and all those you look after:

[Visit Carers UK for more information](#)

Is there any support for my child's mental health at this time?

The Educational Psychology Service is working hard to support children with their mental health. We advise you to contact your school in the first instance so they can signpost you to the right service.

Parents can also self-refer to Exchange counselling service here:

[Exchange Counselling Wales](#)

Swansea Council for Voluntary Service has gathered a host of information to support mental health and wellbeing for children and young people at this time:

[Click here for more information](#)



We have recently lost a close family member and I'm not sure how to support my child who has additional learning needs?

Swansea's Educational Psychology Service have prepared guidance and resources for schools to support children with bereavement and loss. Please contact your school to discuss how your child can be supported at school.

Swansea Council have also commissioned training for school staff across Swansea from Cruse Bereavement to help support children who have been bereaved when they go back to school.

Cruse can also be contacted directly on 01792 462845 or by email at morgannwg@cruse.org.uk.

Additionally, there is also a service called 'Grief Encounter' which is there to support bereaved children and young people. They are open 9am to 9pm, Monday to Friday.

You can call them free on 0808 8020111 or log on to their live web chat for confidential support at www.griefencounter.org.uk. You can also email them on griefftalk@griefencounter.org.uk, and they will respond to all of your questions providing appropriate advice and information.

I am required to return to work soon and am very worried as I have a child with complex needs and it is very difficult to get childcare for them at the best of times let alone now when schools are closed or only partially open. Will I have to give up my job?

We have heard from some parent carers who are being required to return to their workplace. As many supporting services they have previously relied on remain unavailable, they are understandably anxious about their return.

Here are some suggestions which you might find useful:

- Consider discussing your circumstances with your employer to see what arrangements can be made.
- Consider having a 'Carer's Needs Assessment'. If you have already had one, then ask to be reassessed as your personal circumstances have changed. They will be able to offer information and support to help you stay in work.
- Consider joining a worker's union. It is usually cheap to join and unions have extensive resources to support their members in the work place for all sorts of things including those who have dependent disabled family members.

- The Citizens Advice Branch in Newport offers a service specifically around discrimination and employment. They will be able to give you advice from a legal standpoint and they do take on cases should you find yourself in that position. They can be contacted at discrimination@newportcab.org.uk or telephone 01633 222622.
- There is also a grant that you can apply for 5 hours a week additional childcare for children with a disability. Phone the Family Information Service on 01792 517222 and ask for the 'Support Access to Childcare Grant'.
- The Family Information Service can also advise you on all the childcare available in Swansea. Call them on 01792 517222.

There are some excellent websites that offer good advice for working families about their rights in the workplace:

Working Families

and support for your own wellbeing check out:

Wellbeing Through Work



If you still have any unanswered questions or experiences that you want to share with us then please let us know at info@swanseapcf.org.

To receive the next issue direct to your inbox, sign up to our mailing list:

[Sign Up](#)

Acknowledgements

A huge thank you to Swansea Parent Carer Forum members, to parent carers and local parent carer led groups/organisations whose wisdom, experience and voice is so important to our children's and families' future.

