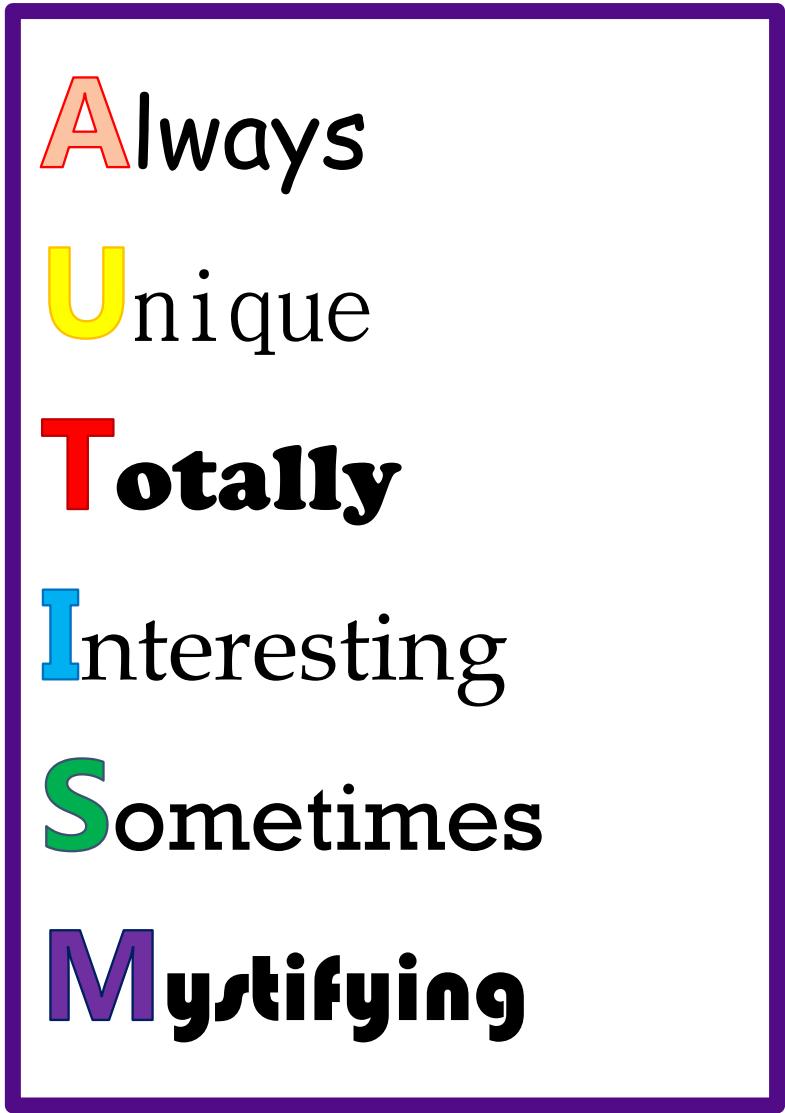


# Autistic Spectrum Disorder pack for parents and carers

Learning Disabilities CAMHS team





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### **What is this pack and who is it for?**

This pack has been developed for parents and carers of young people with a learning disability **and** a diagnosis of an Autistic Spectrum Disorder (ASD). We hope that it will help you to: better understand ASD and some of the common difficulties associated with it; learn about strategies that can be used to support young people with ASD; and find out about additional resources available to you and your child.

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### **Acknowledgements**

We would like to thank the parents who contributed to the development of this pack through allowing us to share their experiences and providing helpful feedback.

*Booklet developed by Dr Amanda Muir and Mr Duncan Dudley-Hicks, LD CAMHS, Oxford Health NHS Foundation Trust*

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## Understanding Autistic Spectrum Disorder

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### *What is an Autistic Spectrum Disorder?*

An Autistic Spectrum Disorder is a lifelong neurodevelopmental condition that affects how a person communicates with and relates to other people. People with ASD tend to experience the world differently from people without ASD. However, everyone's experience of ASD is different. The following animation was designed to help explain Autism to children without ASD, but we think it's also really useful for parents and carers! To access this animation, use the following link: <http://www.smartparenting.com.ph/parenting/big-kids/short-animation-helps-kids-understand-other-kids-with-autism-a1162-20170503> or trying going to YouTube and searching "Amazing Things Happen".

Autism is not an illness or disease and it can't be "cured". However, there are strategies that can be used to support the young person with ASD in a way that can reduce distress and improve their quality of life.



### *Who is affected?*

There are around **700,000 people** in the United Kingdom that have a diagnosis of Autistic Spectrum Disorder – that's around 1.1% of the population.

Autism can affect people of all nationalities, cultures, religious and social backgrounds.



### *Causes of ASD*

The exact cause of ASD is unknown. It is thought that it may occur as a result of genetic and environmental factors.

### **Genetics**

Research suggests that certain genes can make a child more vulnerable to developing ASD. Sometimes ASD can run in families. For example, there are cases of siblings, and more commonly identical twins, developing ASD. However, no specific gene linked to ASD has been identified.

### **Environmental triggers**

Some research suggests that a child born with a genetic vulnerability to ASD will only develop the condition if they are exposed to an environmental trigger. Possible environmental triggers include premature birth (before 35 weeks) and being exposed to alcohol or certain medications (such as sodium valproate) in the womb. There is no conclusive evidence linking an increased risk of ASD with pollution or maternal infections during pregnancy.

## Health conditions associated with ASD

The following conditions are known to be associated with ASD: muscular dystrophy; Down's syndrome; cerebral palsy; infantile spasms; neurofibromatosis; and rare genetic conditions such as fragile X syndrome, tuberous sclerosis and Rett syndrome.

Epilepsy is thought to be more common in people with ASD and a learning disability than people without these conditions.

## *Myths about the causes of ASD*

There is no evidence to suggest that any of the following cause or contribute to the development of ASD:

- The MMR vaccine
- Thiomersal (a compound that contains mercury, which is used in some vaccines)
- The way a young person has been brought up
- Diet (such as eating gluten or dairy products)



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## Common features in ASD

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The degree of difficulties that individuals with Autism experience can vary widely. This is why Autism is referred to as being a 'spectrum' disorder. Although everyone with ASD will have different experiences, there are common areas in which they are likely to experience some difficulties. These include: **social communication & social interaction; repetitive behaviours & routines; special interests; and sensory sensitivities.**

### *Social communication & social interaction*

Social communication relies on our ability to understand both verbal language (what people say) and non-verbal language (body language, tone of voice, facial expression).

Social interaction relies on our ability to recognise and understand how others feel, and to know what is acceptable to say so that other people's feelings don't get hurt.


People with Autism can often struggle with these areas of social communication and interactions and as a result:

- They might understand language very literally



**'I told my daughter to wash her hands in the toilet and she washed them in the toilet bowl instead of the sink'**

- They might say something insensitive or 'seem like they don't care'



**'You haven't been invited to my party because nobody likes you'**

- They might struggle to identify their own feelings or understand why they are feeling a particular way.

- They might struggle to use emotions cards



Emotion cards are often used with people with ASD to help them communicate how they feel. However, if the person cannot recognise how they feel, or cannot relate this to a particular emotion card, this task will be impossible and they might just pick a card because they are being prompted to do so. They might then learn that picking certain cards leads to a particular response!

Also, "sad" to someone with ASD might not be the same thing you mean when you say "sad"!

**Helpful tip!!**

**Rather than asking how someone is feeling, try asking what they have been doing (e.g. what did you do this morning?) You might then be able to help them work out how they are feeling!**

- They might not understand that another person doesn't know what they have done if they haven't seen it

**A young person was using sign language to communicate with someone via facetime, but she was signing behind the phone. She was unable to understand that the person she was talking to couldn't see her hands and so did not know what she was communicating.**

Social imagination is an important aspect of social communication & interaction. It relies on our ability to understand and predict other people's behaviour and to imagine how other people experience the world.

People with Autism can find this extremely difficult and this might result in them:

- Not being able to predict what will happen next in social situations- this will impact on their ability to tolerate change or unfamiliar environments.
- Struggling to understand the concept of danger.

**A young person became extremely distressed when their favourite toy was taken away as they were unable to imagine that it would ever return!**

### *Repetitive behaviours and routines*

People with ASD can experience the world as unpredictable and confusing. They can struggle to understand social contexts making it hard to predict what people will do next. As a result, they might seek certainty and predictability by creating daily routines or set 'ways' of doing things.

**'I really like to do my morning jobs...if I don't do them it feels like a bee in my tummy'**



**A young person might watch the same clip from a TV show or film over and over again, even fast forwarding through the rest of the show to get to this specific clip that they've**

#### **Helpful tip!!**

**Many people with ASD benefit from having a visual planner to help provide them with predictability, which can reduce their experience of anxiety.**





## *Special interests*

People with Autism might have strong interests in activities, objects or people. These can start at a very young age; they can change over time or they can remain the same over many years. It is likely that in young people that have a learning disability the particular interest will be developmentally appropriate rather than age appropriate.

**'My daughter loves hello kitty and will not be without her hello kitty hair band'**

The interest could be related to anything but some common interests include; transformers, Mr Tumble, trains, dinosaurs, road signs, collecting pictures of people.

**'My son prints out pages of transformers. He will do this at any available opportunity'**

Some young people might have interests in unusual areas, such as fascinations with doors, windows, wheels, ribbons etc.

The young person might enjoy talking about and looking at their special interest, but might not be aware that others don't share their interest. Some young people might have a particular item that they need to keep with them.

**'My daughter has special items that she has to have in her backpack with her at all times, such as: a paperclip and the toy casing from a Kinderegg'**

## Sensory sensitivity or sensory processing difficulties

Individuals with Autism often have differences in processing and perceiving sensory information. This means that a person might be under (hypo) or over (hyper)-sensitive to information being processed by one of the seven senses: taste, touch, hearing, sight, smell, balance (vestibular) and body awareness (proprioceptive). It is also possible that a young person might have modulation difficulties within the same sense, for example, they might be particularly sensitive to a high frequency pitch (e.g. fire alarm) but struggle to register other auditory information (e.g. a low tone of someone talking).



If someone is over-sensitive to sensory information they might perceive it very intensely. For example, a background noise most of us can block out is perceived as something very loud, distressing or even painful. If they are under-sensitive to sensory information they might struggle to perceive the information or might miss it altogether. For example, they might have a high pain threshold or not be able to feel extreme temperatures. Having a high pain threshold *and* not being able to understand other people's experiences can sometimes result in behaviour that might hurt others.

**'I don't like people touching me'**

**Imagine that biting your own arm was an enjoyable experience. How would you know that others wouldn't find this enjoyable?**

**'My son will squeeze my arm very hard, he doesn't understand his strength or that this might hurt me'**

## What does this mean for young people with a Learning Disability?

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It is likely that someone who has a learning disability and Autism will not only have difficulties with social interactions, communication and imagination but will also have difficulties learning new skills or transferring skills to new situations. The severity of their learning disability will have an impact on their ability to function independently on a day to day basis and they might appear developmentally behind their same-aged peers.

### *ASD and Emotional Difficulties*

We all feel worried at times, but if this happens a lot or has an impact on our daily lives we call this anxiety.

People with Autism often experience more anxiety day to day than people without Autism. This is because people with Autism often find it hard to understand social interactions, others and the world around them. Therefore, the world can often be experienced as more unpredictable, confusing and threatening- which is scary! The way in which young people respond to their anxiety can be different: some might lash out, whereas others might withdraw.



We can help reduce a young person's anxiety by providing a structure and routine so that their life is more predictable. However, it is likely that people with a diagnosis of ASD will experience some degree of anxiety throughout their life. See strategies section for suggestions on page 13.

### *ASD and Behaviour that Challenges*

Behaviour (including behaviour that challenges) is often a way of communicating our needs and trying to ensure that those needs are met. If the young person has verbal communication difficulties, they will be more likely to use behaviours to communicate their needs.

For example, when we are young we learn that certain behaviours result in particular outcomes, e.g. when we cry as babies our parents comfort us and/or feed us.

If a particular behaviour is effective in achieving our desired outcome, then they will be repeated.

**If you pushed a button and received a £10 note, do you think you would push the button again?**

**If you didn't receive the £10 note the second time would you push it again later?**

## What can cause behaviour that challenges?

When we investigate behaviour that challenges we find that the function often falls into one of the following categories:



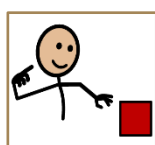
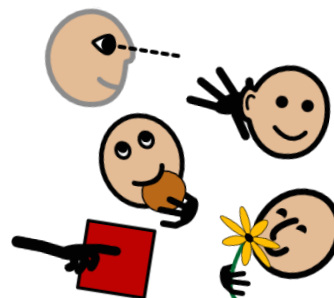
**S**ensory

**P**ain

**A**ccess to tangibles/ **A**ccess to support

**C**ommunicate needs

**E**scape/Avoidance



I want



So if the young person is displaying behaviour that challenges, think about giving them some **SPACE!!**

Here are some examples of the needs that fall into each of the categories (this is not an exhaustive list):

<b>Sensory</b>	<b>Sounds, smells, tastes, feels or looks.</b>
<b>Pain</b>	Urinary Tract Infection (UTI), fever, tummy ache, constipation, tooth ache, head ache, indigestion/reflux etc.
<b>Access to tangibles/ Access to support</b>	I want that toy, I want to do ... now etc. I want someone to interact with me/ help me with my work
<b>Communicate needs</b>	I'm too hot/cold, I'm hungry/ thirsty, I'm scared/upset/worried.
<b>Escape/Avoidance</b>	I want to leave, get me out of here, it's too loud/ busy/ crowded/ difficult etc.

## Triggers

Triggers are events (internal or external) that lead to behaviours that challenge. Triggers can be fast (that occur immediately before the behaviour) or slow (which can occur hours or days before the behaviour). Sometimes young people are able to tolerate one or two triggers but can be less tolerant after experiencing several triggers or a significant change.

Slow Triggers	Fast Triggers
Hunger	Change in routine
Lack of sleep	Stopping favoured activity
Ongoing pain	Acute pain
Upsetting event	Asked to do something too difficult
Puberty	Environment too noisy
Side effects of medication	Being given the 'wrong' cup
Thinking about something	Something being done in the 'wrong' order

### Helpful tip!!

Sometimes, something that is a slow trigger can also be a fast trigger. For example, a young person might become distressed as soon as they learn that their teacher is off sick; at other times they might appear fine and become distressed when they get home at the end of the day.

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## Strategies and Support

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### *What support can LD CAMHS offer you?*

We will soon be offering a post diagnostic support group for parents and carers where we will provide the following:

- A space to understand the ASD diagnosis, and to consider how it has impacted you and your family.
- Sharing our top tips for supporting a young person with ASD through a range of experiential activities.

If the young person's behaviour is particularly challenging we can work with you and the other people in the young person's support system (e.g. school, social care and respite) to:

- 1) Develop an understanding of the function of the behaviour
- 2) Think about the different ways to meet the young person's needs

### *Can you do anything?*

You are probably doing a lot to support the young person you care for and if you haven't already we would recommend trialling the following simple strategies to continue your great work.

It is important to remember that making even small changes might increase the young person's level of anxiety and so you might initially see an increase in behaviour that challenges. We would recommend only doing one change at a time and keeping with it because the initial level of anxiety should reduce.

### *Health checks*

A good first step is to rule out any health difficulties that could be causing pain. Take the young person to the doctors and/or dentist for regular check-ups. Due to the high level of sensory impairments in people with learning disabilities, it is also useful to ensure that they receive regular eyesight and hearing tests.

### *Strategies*

#### **Try to set a regular structure and routine**

Some starting points might include:

- Setting consistent meal times each day
- Setting consistent snack times throughout the day
- Developing a bed time routine and keeping this the same every night

Support the young person to understand what you are saying by using meaningful pictures or photographs (e.g. on a mobile phone or iPad).

Examples might include using:

- An egg timer or a sand timer to help the young person wait - remember some young people will prefer one that ticks whilst others will not be able to tolerate the noise (see page 20).
- Now and next cards (e.g. a picture of the current activity and a picture of the next activity). If the young person struggles when plans are changed last minute, try using weather cards to help them anticipate a possible alternative activity (see page 21).
- Visual timetable or calendar (see pages 22-23)

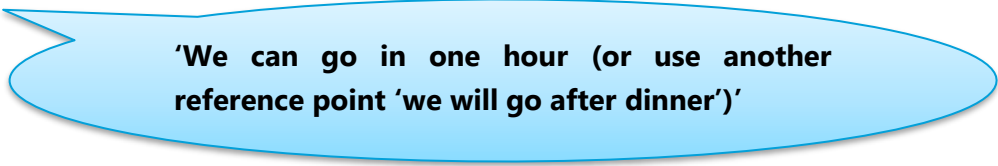
Use short simple sentences.

- Avoid using sayings (e.g. I'll take your word for it) or abbreviations (e.g. OMG). Say what you mean!



**'go to the bathroom and wash your hands in the sink'**

- Be specific! Avoid saying 'maybe' 'soon' 'later'



**'We can go in one hour (or use another reference point 'we will go after dinner')'**



**'The shop is closed today!'**

Break steps down- ask them to do one thing at a time (when they are more able/ comfortable with a task then the number of steps could be increased).

Talk about positives rather than focusing on negatives or when things have gone wrong. For example, rather than saying 'don't stand so close to me', try 'can you show me good personal space? Well done!'

Try not to give them too many options and instead use a forced choice, i.e. would you like an apple or a pear (ensure that they like both options). This helps to give them some control but isn't overwhelming.

### Try Anchoring activities to concrete aspects of the environment

Many young people that have a learning disability and ASD struggle to understand time. This means that they will struggle to understand if you ask them to wait 1 minute or 5 minutes. For someone who doesn't understand time, asking this can be as anxiety provoking as using vague terms like 'later'.

It can be helpful to **anchor** activities, tasks, and access to items with something that the young person can clearly relate to their environment. This can be particularly useful if the young person doesn't understand or is distressed by using timers (i.e. digital, egg, sand etc.).



#### Helpful tip!!

**Here are a few examples, make sure you always follow through with what you have agreed at the time you have agreed!**

*When your sister comes home from school you can have a snack*

*When Mr tumble comes on the TV you can have ... (it is important to note that you can use digital devices to have more control about when shows are played on the TV/iPad)*

*When Daddy gets home we will ...*

Additionally, you can use something they enjoy instead of a sand timer to support them to wait, for example:

*When Thomas the tank engine finishes, we will go to the park ...*

*When the song finishes, we will have dinner*



### *Special occasions/ holidays*

Often individuals with ASD will not have the same interests as their peers which might include birthdays, Christmas and holidays. This can be difficult for parents especially when trying to mark the special event with a party or gift. You're not alone in this struggle! We would suggest using the young persons interest to mark an occasion even if this means yet another robot or more time on the iPad!



You could also try to:

- ★ Buy gifts that are related to the young person's interest
- ★ Go on days out that are linked to the young person's special interests (e.g. JCB land or the train station)
- ★ Go to familiar places
- ★ Limit the number of places that you visit on a single holiday



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### **Final words**

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We hope that you have found this pack helpful. We have tried to provide you with the foundations for understanding ASD and basic strategies that you can try to implement at home. There are many more that might be helpful; however, we suggest that you begin with the foundation strategies outlined in this pack.

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## Resources

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### General Information and Signposting

#### Video explaining ASD to other children (but it is good for parents too!)

<http://www.smartparenting.com.ph/parenting/big-kids/short-animation-helps-kids-understand-other-kids-with-autism-a1162-20170503>

or directly at:

<https://www.youtube.com/watch?v=7JdCY-cdgkI>

#### Autism Family Support

The Autism Family Support Project (AFS) offers information, training, advice and support to families of children and young people on the autism spectrum in Oxfordshire.

AFS also runs a befriending scheme, weekly youth groups and school holiday activities for youngsters with high functioning autism and Asperger's syndrome, training for parents, young people and professionals.

Contact:

Becky Loveless  
Thomley Hall Centre  
01844 338696  
[becky@autism-fs.org.uk](mailto:becky@autism-fs.org.uk)

#### National Autistic Society (NAS)

Leading UK charity for Autism - great source of information  
Find out information about family days out, benefits, autism friendly cinema screenings in Oxfordshire.

<http://www.autism.org.uk>

#### OASIS

Oxford based parent led charity, which offers information and support to parents and carers of children with an Autistic Spectrum Disorder

They organise holiday Play Days for children and their families in Oxfordshire.

<http://www.oasionline.org.uk>

#### Early Bird Plus Programme

Courses for families with a child aged 5-8 years with a diagnosis of Autistic Spectrum Disorder. Courses also available for schools/professionals.

Contact: Tel: 01865 456704

#### Educating Autism

[www.educateautism.org.uk](http://www.educateautism.org.uk)

**Pathological Demands Avoidance  
Society**

[www.pdasociety.org.uk/](http://www.pdasociety.org.uk/)

**Autism Education Trust**

AET is dedicated to coordinating, supporting and promoting effective education practice for children and young people on the autism spectrum.

[www.autismeducationtrust.org.uk](http://www.autismeducationtrust.org.uk)

**Parents talking about Aspergers**

<http://www.parents-talking-aspergers.co.uk/>

**Inclusion Support (Short Breaks) Scheme**

Available for children from birth to 17 years of age with emotional, behavioural or learning difficulties. Funding can only be accessed by families on low income/benefits with disabled children. The priority for this scheme is to support access to out-of-school activities and/or holiday activities.

Contact Name: Pauline MacKinnon

Telephone: 08452 26 26 36

**Autism Oxford**

Their mission is to spread awareness of the realities of life on the autism spectrum and support the development of autism services. They organise training events, sign post enquiries to relevant services, and manage the Oxfordshire Autism Alert Card.

You can download an application for an Autism Alert Card on the website.

<http://www.autismoxford.org.uk>

Contact: 01844 353292

**Thomley Activity Centre**

Specialist play equipment, loan library, sensory room, arts & crafts, games, ball pit, outdoor activities, bikes, swings.

Call 01844 338380 or visit  
[www.thomleyhall.org](http://www.thomleyhall.org).

**SENDIASS**

Special educational needs and disability information, advice and support service.

For more information about SENDIASS

Oxfordshire phone: 01865 810516 or  
text: 07786 524294. Web:

[www.oxfordshire.gov.uk/sendiasm](http://www.oxfordshire.gov.uk/sendiasm) email:  
[sendiasm@oxfordshire.gov.uk](mailto:sendiasm@oxfordshire.gov.uk)

### **Communication and Interaction Service**

Part of the Oxfordshire SEN (special educational needs) support services. Communication and interaction are about to offer tailored support to schools in working with a child on the autistic spectrum. They can be accessed through school.

### **Cerebra**

National charity supporting children up to 16 years with neurodevelopmental disorders including ASC/ASD.

Email: [info@cerebra.org.uk](mailto:info@cerebra.org.uk) Tel: (freephone): 0800 328 1159

### **Education and Health Care Plan (EHCP)**

These are used by education and health care to ensure that the needs of the young person are met.

If the young person doesn't have an EHCP then please talk to the school and they can initiate this process.

### **Young Carers**

<https://www.oxfordshire.gov.uk/cms/sites/default/files/folders/documents/socialandhealthcare/carers/youngcarers/asignpostsforsupportforyoungcarers.pdf>

### **Carol Gray Social Stories**

Carol Gray developed social stories in 1990. Social Stories are a social learning tool that supports the safe and meaningful exchange of information between parents, professionals, and people with autism of all ages.

<https://carolgraysocialstories.com/social-stories/>

### **Occupational Therapy Links**

#### **Sensory Integration and Processing**

<http://www.oxfordhealth.nhs.uk/children-and-young-people/wp-content/uploads/sites/4/2014/05/Sensory-Processing-presentation-February-2014.pdf>

#### **Sensory Activity Worksheets**

<https://www.oxfordhealth.nhs.uk/childrens-occupational-therapy/resources/>

## Visual Timers



There are different types of visual timer and the young person might respond better to one over another. It will be worth trialling a timer to see if the young person responds to this.

To support the young person to wait, we advise explaining what the timer is for to the young person when they are feeling calm. Say:

'When all of the sand gets to the bottom I will be able to help you'

'When the time gets to 0 we will move on to .....

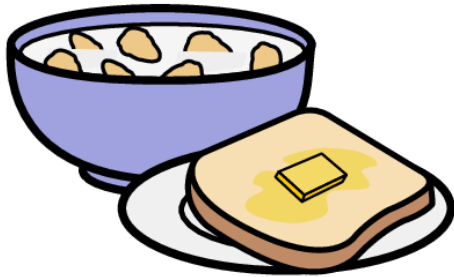
When using the visual timer for the first time start by setting a short amount of time (10 seconds). As soon as the timer finishes respond by completing the action that you have asked them to wait for. Praise them for waiting.

Slowly and gradually increase the length of time that the timer is set for, i.e. 20 seconds, 40 seconds, 1 minute, 5 minutes etc. Each time the timer finishes ensure that you immediately follow through with what you have asked them to wait for and continue to praise them for waiting.

### Now & Next visuals

Now and next cards are used to show the young person what task they are currently doing and what task is next. When explaining this to the young person go to their level (sit down with them or crouch down) and say 'now we are doing .....' next we are doing.....' Once they have completed the now activity remove the card and put this away.

**Now**



BREAKFAST

**Next**



Playground

### Weather cards

Weather cards can be used to help develop routine and structure. These help to show the young person what activities can be done instead of an outdoor activity if the weather is bad (raining etc).



### Visual planner/ Visual timetables

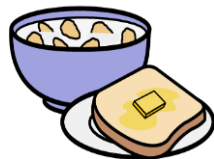
There are many different styles of visual timetable. It is important to identify one that the young person can manage and understand. Some young people find it extremely difficult to wait for a highly desirable activity, in this case we would suggest putting a 'free choice' time on the timetable. The 'free choice' should be a restricted choice of a couple of activities including the favoured activity that they wouldn't have been able to wait for. Some young people will struggle if there are too many activities planned in their day. In this case you should think about doing a 'morning' and 'afternoon' timetable, so that the number of activities doesn't appear overwhelming. Other young people like to have their whole week or even two weeks planned out!

### Daily Planner

#### Monday Morning



Get Dressed



Breakfast

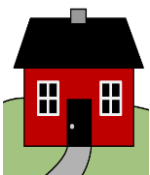


Brush Teeth



School

#### Monday Afternoon



HOME



SNACK



Trampoline



Dinner



Reading



Bath



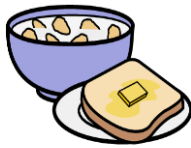
Bed

Weekly Planner

MONDAY



TUESDAY



WEDNESDAY



THURSDAY



FRIDAY





Please contact us if you would like the information in another language or different format.

**Arabic** يُرجى الاتصال بنا إذا كنتم ترغبون في الحصول على المعلومات بلغة أخرى أو بتنسيق مختلف.

আপনি এই তথ্য অন্য ভাষায় বা আলাদা আকারে **Bengali** পেতে চাইলে অনুগ্রহ করে আমাদের সাথে যোগাযোগ করুন।  
**Urdu** اگر آپ یہ معلومات دیگر زبان یا مختلف فارمیٹ میں چاہتے ہیں تو برائے مہربانی ہم سے رابطہ کریں۔

**Chinese** 若要以其他語言或格式提供這些資訊，請與我們聯繫

**Polish** Aby uzyskać informacje w innym języku lub w innym formacie, skontaktuj się z nami.

**Portuguese** Queira contactar-nos se pretender as informações noutra idioma ou num formato diferente.

Oxford Health NHS Foundation Trust  
Trust Headquarters  
Warneford Hospital  
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Concerns and complaints

We aim to provide you with a high quality service at all times. However, if you have any concerns, complaints or comments about your experience of our service then please tell a member of the team or contact the Patient Advice and Liaison Service on freephone: 0800 328 7971.

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