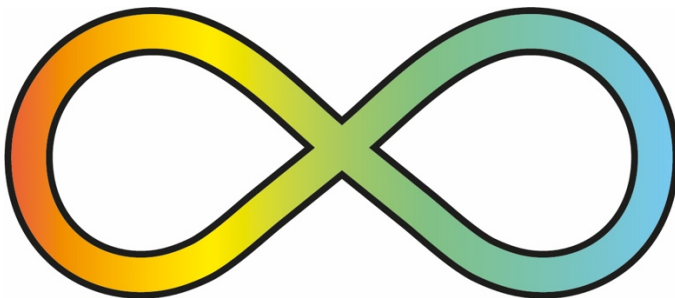


# Information for patients and carers

## Autism Spectrum Disorder Post Diagnostic Pack

Parent/Guardian of 0-8 years old



Dear Parents and Carers,

This leaflet has been prepared by the Community Paediatrics ASD (Autism Spectrum Disorder) Team. The wording is addressed to parents, but it will also be of benefit to carers and families of young children diagnosed with autism.

Coming to terms with diagnosis of autism can feel overwhelming. It takes time to adjust and understand what this means for the child, you, and those working with your child. We have created this pack of important information, from trustworthy sources, to help you understand autism and to give you information about support available for you and your child.

This pack includes information from The National Autistic Society and Lancashire County Council in addition to other sources and information on diagnosis, financial support, some helpful tips, and other valuable resources for support.

As a service the terminology we use is ASD in line with DSM5 (Diagnostic and Statistical Manual of Mental Disorders) criteria, however we acknowledge different terminology can be used including:

- Autism
- ASC (Autism Spectrum Condition)
- ASD (Autism Spectrum Disorder)

To develop this pack we collaborated with clinicians, education professionals, and parents of children with autism to ensure the information provided is helpful.

Kind Regards,

Community Paediatrics ASD (Autism Spectrum Disorder) Team

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## Introduction to Autism

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### **What is Autism?**

Autism is a lifelong neurodevelopmental condition that affects how people perceive the world and interact with others. Autism may impact social communication and the ability to think flexibly; children with autism can have some difficulties with processing sensory information and will have some restricted and repetitive behaviours.

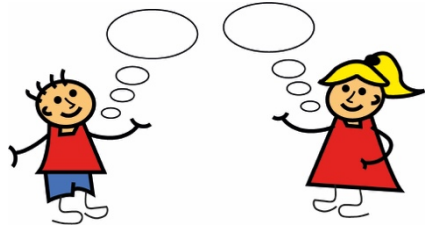
Autism is a spectrum disorder. All children with autism share certain difficulties, but it affects each child differently. Children with autism may experience high levels of anxiety as understanding and relating to other people, and taking part in everyday family, school, and social life, may feel overwhelming.

Autism is much more common than most people think. About one in a hundred children have autism in the UK. People of all genders, races, ethnicities, and economic backgrounds can be diagnosed with ASD (Autism Spectrum Disorder).

The appearance of autism can vary from child to child. Some children with autism may be verbal and engaged, while others may be non-verbal and introverted or any state in between. Children with autism usually have some difficulties in the areas of:

## Communication:

Communication difficulties are a common trait of autism. Children with autism may take longer to understand what others are saying and struggle to effectively communicate their own needs,



which can often lead to frustration. They may become confused when too much information is given to them all at once, they may take things literally and not understand abstract concepts.



### Helpful tips:

- **Use pictures and written information to complement instructions**
- **Use social stories or visual schedules to support an individual to cope or adjust to changes in routine**
- **Rather than giving a whole list of instructions, try to break them down into one instruction at a time**
- **Instead of asking how your child is feeling, try asking what they have been doing. This may help you work out how they are feeling**

## **Flexible thinking and Imagination:**

Children with autism may have difficulties with flexible thinking. This means that they often like routine, and when that routine changes it can be an incredible source of stress. It may be difficult for them to adapt to alternative daily activities or to accept when things are not as they expected. They often prefer to always travel to school the same way or eat the same food for breakfast. They often feel anxious or confused by the unpredictable world. They may hyper-focus on a specific interest and be adept at focusing on detail.



### **Helpful tips:**

- **Create schedules or to-do lists; a visual planner can help with providing predictability and reducing anxiety. Preparing your child for changes in advance can help to avoid confusion**
- **If your child has a special interest, think of using it to learn about other things; for example, an interest in trains can help a child to learn about geography**

## **Social interaction:**

Children with autism may have a different social interaction style than children without autism. They may find it difficult to work out what other people are thinking or feeling. It may be difficult for them to focus on a conversation, for example because of the background noise, bright lights, or busy environment. They may struggle to learn the 'social rules' and may have a preference for talking about their special interests. They may prefer fact-focused communication and can have difficulties with understanding hints, implementing meaning or assumptions. They may feel anxious or fearful in unfamiliar places or with unfamiliar people because they find it difficult to make sense of what they see and hear.

### **Helpful tips:**



- **Practice play skills, for example by taking turns in games and sharing toys**
- **Practice conversation skills, for example by choosing what to talk about or what body language to use. Use words or pictures as prompts for different conversation topics**
- **Use pictures to help your child learn a game, for example, pictures could represent different steps in a restaurant play sequence – take the order, cook the food, serve the food, clear the table, pay the bill**
- **Social stories can be an effective way to teach your autistic child skills like communicating and joining in with others**

<https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-conversations>





## Sensory Processing:

Most children with autism may experience sensory information differently. One or several senses may be affected, e.g. light, sound, touch, taste, smell, bodily movement, balance or spatial orientation, temperature, and internal physical body states such as feeling hungry or knowing when to use the toilet. A child may be extremely sensitive or not notice differences in sensation at all. If they are over-sensitive to sensory information they may struggle with things like background noise, they are unable to block it out and can find it distressing or even painful. If they are under-sensitive, they may have a high pain threshold or not be able to feel hunger or extreme temperatures.

### Helpful tips:



- **Think about what your child's sensory preferences and sensitivities are, what helps, what causes distress?**
- **For the child who becomes agitated by touch, allow them to stand at the front or back of the queue to avoid being bumped. Allow them to transition to the next lesson three minutes before others, to avoid corridor collisions**
- **For the child who seeks hugs, try Lycra undergarments, rash vests and rugby base layers that are cheaply available from many sports outlets. Weighted lap pads and blow-up canoe chairs are also useful**

- Follow this link for a video about joining in with sensory differences

<https://www.nhsggc.org.uk/kids/life-skills/joining-in-with-sensory-differences/>



For more Sensory tips and information please scan the QR codes below:



## Sleep difficulties:

Children with autism may often have trouble sleeping. They may struggle to get to sleep, stay asleep or to wake early. Sensory sensitivities, anxiety, a lack of daytime/nighttime routines or unhelpful routines can have a big impact on sleep. Some sensory sensitivities such as increased sensitivity to blue light from smart phones, laptops and other screens, or sensitivity to certain sounds or white noise, which may be upsetting or distracting and keep your child awake. Some children with autism may be experiencing social cueing problems, where they do not make the connection between others in the house going to bed and their own need to sleep. Creating a healthy sleep routine can significantly reduce anxiety and help to improve sleep.



## Helpful tips:



- Try to explain sleep using social stories, you can also use them to reassure your child that they are safe when sleeping
- Keep a sleep diary to detect any unusual patterns of sleep and identify factors that may be affecting your child's ability to sleep
- Reduce your child's screen time before bed
- Make the bedroom more comfortable, for example by using black out curtains, reducing noise by using thick carpets, block out noise by using ear plugs and remove distractions such as electronic devices
- Use relaxing techniques such as having a bath, massage, quiet time, or gentle exercise such as yoga

## Eating difficulties:

Some children with autism may experience problems associated with eating, for example issues with taste, texture and smell of foods, difficulty trying new foods, wanting the food to not touch other foods, overeating (not realising they are full) or under eating or having a restrictive palate. A balanced diet is important for overall health and growth. Do not worry if your child is eating foods from each of the main food groups and if they are growing well. Palates can change so do not give up on offering new foods, but always use no pressure approach. Please visit your GP if you are concerned about your child's eating habits.



Follow the following link for 32 steps guide to eating:

<https://www.stargoldfoodfairy.com/wp-content/uploads/2018/06/32-Steps-To-Eating-STARGOLD-04-23-18.pdf>



### Helpful tips:

- **Disguise vegetables by blending them and mixing into meals**
- **Cut foods into shapes related to your child's special interest**
- **Build acceptance to new foods through gradual exposure**
- **Have set times for meals and stick to them**
- **Encourage your child to explore, play and get messy with the food**

## **Behaviours that challenge:**

Children with autism are more likely to show behaviour that challenges more than children without autism. Behaviour that challenges is usually triggered by one of the five main reasons: sensory, pain, communication needs, escape/avoidance, access to tangibles/support. Behaviour that challenges is always functional (it achieves something for the person).

Follow this link for Quality of Life at Home toolkit instructive videos created by Ambitious About Autism:



<https://www.ambitiousaboutautism.org.uk/informationabout-autism/health-and-wellbeing/physical-mental-wellbeing/quality-of-life-at-home>

### **Helpful tips:**



- **Understanding the cause of a behaviour is the key to dealing with behavioural problems. Learning about autism can help you understand what triggers your child's behaviour that challenges**
- **We highly recommend that you attend the ERIN (Education, Resources, Interventions, Networking) (0-5 years old) or Cygnet (5 and older) workshops to gain better understanding of autism. To access the courses please contact your**

**Paediatrician or contact the LD Team  
on [LDRReferralHub@lscft.nhs.uk](mailto:LDRReferralHub@lscft.nhs.uk)**

## Toileting:

Some characteristics of autism can lead to difficulties with learning to use the toilet. On average, children on the autism spectrum learn to use the toilet later than typically developing children as the traits of autism can interfere with learning this skill. Children with autism can behave in challenging ways, for example, they may be afraid of the toilet, continually flush the toilet, smear poo on the wall and other places, or refuse to poo. Children with autism thrive on routine and learning to use the toilet is a big routine change.

Follow this link for more information about toileting and toilet training:

[https://sparkforautism.org/discover\\_article/toilet-training-autism/#:~:text=On%20average%2C%20children%20on%20the,of%20children%20with%20developmental%20delay.](https://sparkforautism.org/discover_article/toilet-training-autism/#:~:text=On%20average%2C%20children%20on%20the,of%20children%20with%20developmental%20delay.)



Developing toileting plan:

<https://www.milestones.org/resources/tool-kits/toilet-training-tool-kit/developing-a-toileting-plan#:~:text=By%20repeating%20the%20toileting%20routine,independent%20access%20of%20the%20toilet.>





## Helpful tips:

- Use a visual sequence beside the toilet to help your child understand what is expected of them, for example: trousers down, pants down, sit on the toilet, wee/poo in the toilet, wipe (you may need to show how many squares of paper to take), pants up, trousers up, flush toilet, wash hands. Follow this link to a sample picture toileting routine: <https://do2learn.com/picturecards/printcards/s elfhelp toileting.htm>.



- Use reward systems and gradually require more of your child before giving them a reward, for example: Have them sit 10 seconds, praise them for doing so, and immediately give a reward for cooperating. Bring the child to the toilet every 30 to 60 minutes, and gradually increase the amount of time they sit until it reaches 3 minutes. Eventually, they will only get a reward when they urinate or have a bowel movement in the toilet
- Observe your child's toileting patterns and build a daily schedule around the time your child typically needs to use the toilet. You can use the following chart to record your child's patterns:

<https://www.milestones.org/files/legacy/2015/07/ELI MINATION-PATTERNS-AND-DAILY-INTAKE-REC-final.pdf>





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## Education

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### **SEND (Special Educational Needs and Disability) support for early years settings.**

Additional help in school is provided in a graduated way. Schools provide Universal high-quality teaching, they can also provide SEND (Special Educational Needs and Disability) Support and, if that is not sufficient, an EHCP (Education, Health, and Care Plan) can be initiated. Not all children with autism have a learning disability and many may not need an EHCP.

Specialist teachers work with private, voluntary, independent, and maintained early years providers around their roles and responsibilities in relation to SEND (Special Educational Needs and Disability). This includes:

- New early years SENCO (Special Educational Needs Coordinator) induction
- early years SENCO network meetings
- 'Request for Involvement' (to support early identification and early intervention)

Specialist teachers also provide ongoing information, advice and interventions to support young children with identified SEND, and the practitioners that work with them, in the settings they attend.

Specialist higher level teaching assistants (HLTA) support specialist teachers and may carry out some direct work in settings to support practitioners. The work of the specialist HLTA may include:

- Modelling, developing strategies, routines and resources
- Using the Assessment, Tracking and Target Setting (ATTS) tool
- Advice and support on the graduated response ('assess, plan, do, review')

## Contact details

Specialist Teaching Service Inclusion Service:

**01524 581200** [Inclusion.north@lancashire.gov.uk](mailto:Inclusion.north@lancashire.gov.uk)

**01772 531597** [Inclusion.south@Lancashire.gov.uk](mailto:Inclusion.south@Lancashire.gov.uk)

**01254 220553** [Inclusion.east@lancashire.gov.uk](mailto:Inclusion.east@lancashire.gov.uk)

### Postal address:

Inclusion Service

PO Box 100

County Hall

Preston

PR1 0LD

### EHCP Overview

An education, health and care plan (EHCP) is a plan for children and young people aged up to 25 who need more support than is available through special educational needs (SEN) support.

It is a legal document that describes their special educational, health and social care needs.

It explains the extra support that may be provided to help meet your child's needs and how this will help them to make progress and achieve their goals.

The first step is to ask Lancashire County Council, as the local authority, for an EHCP needs assessment.

After a request is made, there are three things that may take place:

1. A decision to go ahead with an assessment or not,
2. A decision to issue an EHCP or not,

3. Work to develop and agree the plan.

The following short film from Independent Support, with support from the Department for Education, explains what an education, health and care plan is and who can have one.

[https://www.youtube.com/watch?source\\_ve\\_path=Mjg2NjQsMTY0NTAz&feature=emb\\_share&v=ughC-a5RhAc](https://www.youtube.com/watch?source_ve_path=Mjg2NjQsMTY0NTAz&feature=emb_share&v=ughC-a5RhAc)



To find out more you can also ring **SEND helpline 01772 533900**.

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## Benefits

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You might be entitled to claim some benefits for your child. Some of which are available regardless of the household income or employment status, these may include:

- Disability Living Allowance (DLA)
- Carer's Allowance
- Extra Child Tax Credit
- Income Support or Universal Credit
- Housing benefits or Council Tax reductions

For more information please visit:

<https://www.northlancsdirectionsgroup.com/benefits-advice>



or

<https://www.autism.org.uk/advice-and-guidance/Topics/benefits-and-money/benefits/benefits-you-can-get/benefits-for-autistic-children>.



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## Funding

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Children with autism and their parents and carers may be entitled to financial support and social security benefits. For more information, please follow the links below:

**Disability grants:** <https://www.autism.org.uk/autism-services-directory/d/disability-grants>



**Information about financial help for your family including carer's allowance and help with travel costs:**

<https://www.gingerbread.org.uk/find-information/parenting-perspectives/parenting-disabled-child/>



**Funding for vital specialist equipment:**  
<https://newlifecharity.co.uk/equipment-grants/>



**Family Fund:** <https://www.familyfund.org.uk/grants-england>



**Grants and funding for voluntary and community organisations:** <http://www.lancaster.gov.uk/information/grants-to-voluntary-organisations>



**A World UK CIC non-profit organisation supporting the autistic community across the North of England and the Midlands offering funded holidays and funded horse riding:**

<https://www.theaworlduk.com/our-services>



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## What can help behaviours that challenge

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Behaviours that are labelled as 'difficult' or 'challenging' often serve a purpose, such as communicating when something is wrong. To understand what your child is trying to achieve by behaving in this way, try to think what has occurred before, during and after your child's difficult behaviour to break down and reflect on each event. Behaviour difficulties may arise due to:

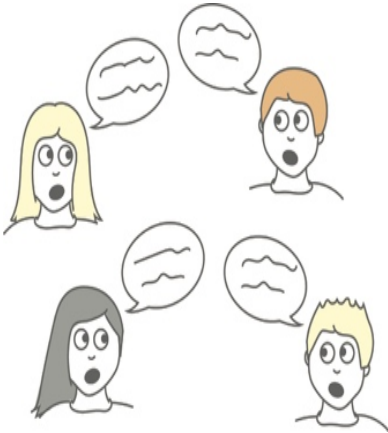
- Confusion or fear produced by unfamiliar events and situations
- Changes in routine
- Difficulty understanding instructions or what is expected
- Not understanding social rules
- Finding it difficult to understand and express feelings
- Over-sensitivities to different sensory stimulants e.g. noise, light, touch
- Specific fears of situations or objects
- Pressure to do tasks that are too difficult

### General strategies that can be helpful:

	<p><b>Managing emotions</b> Relaxation – Deep breathing, thinking positively, redirection to pleasant, calming activities. Anger management – Identify the physical sensations that signal agitation and develop a range of alternative activities to help them calm down e.g. breathing, counting. Zones of regulation - A visual prompt to help your child express and communicate how</p>
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they feel

<https://thezonesofregulation.com>



### **Communication**

Allow your child to take part in social opportunities appropriate for them.

Use simple language that your child will understand, avoid sarcasm or metaphors.

Think about visual aids to help your child understand – for example, show them a photo of what you are talking about.

Present information in the order in which they will happen.

Be patient and speak slowly to allow your child to process the new information.

Avoid raising your voice if your child is angry or upset. They are not likely to fully understand you in this state, so if possible, wait to talk to them later. Try to stay calm and offer helpful strategies for them, such as taking some deep breaths together.





### **Routines and environment**

Keep the environment around the child as calm as possible with minimal stimulation.

Organisation: set out expectations e.g. what you expect from your child/what they can expect from you/others.


Consider using visual aids such as a visual timetable or written list, to provide visual cues for your child.



### **Rewarding desirable behaviours**

Positive reinforcement involves strengthening a particular behaviour by rewarding it with something desirable such as favourite food, toys, activity or verbal praise.

Token systems can also be used in which your child collects points, ticks, stars, stickers for desired behaviour. Specify exactly what you want when giving an instruction. For example, 'can you stop that right now' is clearer than 'can you stop that'. This clarity helps your child understand your expectations and gives them a better chance of success.

	<p><b>Distraction/redirection techniques</b></p> <p>Redirecting your child's attention to a preferred topic of conversation or activity can be an effective way of preventing a situation getting worse or diffusing a difficult situation.</p>
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## Hospital Passport

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The hospital passport is designed to give hospital staff helpful information about your child and their health needs. It also has other useful information, such as your child's interests, likes, dislikes, and any reasonable adjustments that they might need, for example communication and sensory needs. The Hospital Passport can help you feel supported and reassured that your child will receive the right care.

To access the digital version of this passport please go to:

<https://www.lancsteachinghospitals.nhs.uk/media/.resources/619e28d5df1d49.95281303.pdf>



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## Other support and resources

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### Lancashire Local Offer

Website:

<https://www.lancashire.gov.uk/children-education-families/special-educational-needs-and-disabilities/>



Local Offer Facebook page:

<https://www.facebook.com/LancashireLocalOffer>



Lancashire County Council SEND Newsletters

<https://www.lancashire.gov.uk/children-education-families/special-educational-needs-and-disabilities/getting-help/family-information-network-directory/>



Special Educational Needs and Disability Information Advice and Support Service (SENDIASS) [www.lancssendias.org.uk](http://www.lancssendias.org.uk)

Telephone: **03001236706**

Email: [information.lineteam@lancashire.gov.uk](mailto:information.lineteam@lancashire.gov.uk)



If you would like to access other support services and groups in your area you can find these via the Lancashire Local Offer, on the Lancashire County Council

Website: [www.lancashire.gov.uk/SEND](http://www.lancashire.gov.uk/SEND)



Lancashire Healthy Young Person and Family Service Now HCRG [www.lancsyoungpeoplefamilyservice.co.uk](http://www.lancsyoungpeoplefamilyservice.co.uk)



Lancashire County Council Children, education and families' information [www.lancashire.gov.uk/children-education-families](http://www.lancashire.gov.uk/children-education-families)



**Sensory advice**

<https://www.locala.org.uk/services/sensory-occupational-therapy-service/talking-sense-training>



**Sleep advice and support:**

<https://thesleepcharity.org.uk>



**ADDvanced Solutions -Supporting you to find the answers:**

<https://www.advancedsolutions.co.uk/resources/parents-carers-and-professionals.html>



**Facebook groups:**

[https://www.facebook.com/events/787128993303435/?acontext=%7B%22source%22%3A%2229%22%2C%22ref\\_notif\\_type%22%3A%22plan\\_user\\_invited%22%2C%22action\\_history%22%3A%22null%22%7D&notif\\_id=1711540634078057&notif\\_t=plan\\_user\\_invited&ref=notif](https://www.facebook.com/events/787128993303435/?acontext=%7B%22source%22%3A%2229%22%2C%22ref_notif_type%22%3A%22plan_user_invited%22%2C%22action_history%22%3A%22null%22%7D&notif_id=1711540634078057&notif_t=plan_user_invited&ref=notif)



NLDG Facebook page for information

<https://www.facebook.com/NLDGAdditionalNeedsSupport/>



NLDG Facebook group for advice on services and support from 800+ local families with children with various additional needs

<https://www.facebook.com/groups/NorthLancsDirectionsGroup>



**Navigate: emotional support for parents:**

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

<https://www.scope.org.uk/family-services/navigate/eligibility-check/>



## Gender identity and autism:

National Autistic Society link <https://www.autism.org.uk/advice-and-guidance/what-is-autism/autism-and-gender-identity>



## Girls and autism

National Autistic Society webpage  
<https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls>



<https://autisticgirlsnetwork.org/>



<https://thegirlwiththecurlyhair.co.uk/>



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## Local sport and play groups

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Children and Family Wellbeing Service – to check the latest activities and available services please follow the link:

<https://www.lancashire.gov.uk/children-education-families/family-hubs/south-ribble-west-paddock-family-hub-and-the-zone/>



or like their Facebook page:

<https://www.facebook.com/profile.php?id=100064529776527>



Dance classes - <https://dancesyndrome.co.uk/>



**Sport Group** - Ran by Local Hockey team in partnership with the offer to help engage young people to make friends, follow instructions, have fun and help with motor skills. Every last Sunday of the month (free) email phoenixflyerz@outlook.com to make contact.



**Disability Football** - Free Disability football coaching in the indoor training hall at UCLAN Sports Arena from 9:15-10:15am every Saturday for children/young people aged 4 to 16years.

**PAN-Disability Coaching** (meaning that any disabled person can take part) for Footballers on a Friday evening at Playfootball.net from 6pm -7pm. The cost is just £3.00 per session – everyone is welcome!

Play.net is located at:

PlayFootball Preston  
Tulketh Community Sports College  
Tag Lane  
Ingol  
Preston  
PR2 3TX

## Contact details

Should you require further advice or information please contact:

Email: [ASDinfo@lthtr.nhs.uk](mailto:ASDinfo@lthtr.nhs.uk)

**Follow us on social media @lancshospitals**

**Lancashire Teaching Hospitals NHS Foundation Trust is not responsible for the content of external internet sites.**

All our patient information leaflets are available on our website for patients to access and download:

[www.lancsteachinghospitals.nhs.uk/patient-information-leaflets](http://www.lancsteachinghospitals.nhs.uk/patient-information-leaflets)

Lancashire Teaching Hospitals is a smoke-free site. Smoking is not permitted anywhere on any of our premises, either inside or outside the buildings. Our staff will ask you about your smoking status when you come to hospital and will offer you support and advice about stopping smoking this will include Nicotine Replacement Therapy to help manage your symptoms of withdrawal and the opportunity to speak to a nurse or advisor from the specialist Tobacco and Alcohol Care Team.

If you want to stop smoking, you can also contact Smokefree Lancashire on Freephone **08081962638**

**Please ask a member of staff if you would like help in understanding this information.  
This information can be made available in large print, audio, Braille and in other languages.**

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**Division:** Women & Children’s Division  
**Production date:** July 2024  
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