Further Support

The Children and Family Wellbeing Service offer time limited family support in the home and in centres in groups and Parent Programmes. There are also evidence-based courses on offer that families may benefit from including Group Triple P for parents of children aged 0-11, Teen Triple P for parents of children aged 12-19 and Stepping Stones Triple P which is for families with pre-adolescent children with additional needs. For further information please contact Lune Park Neighbourhood Centre 01524 581280

AOK Parent peer support group for children with additional needs with / without a diagnosis aged 0-8. Stay and play for pre-school children term time and up to age 8 during the school holidays. Advice, information and support for parents and carers. Wednesdays 1.00-3.00 Lune Park Neighbourhood Centre LA12LN 01524 581280



Scan this QR code with your smart phone camera to go the North Lancs Directions Group Website



Version 4 June 2019 North Lancashire Directions Group

This booklet is also available at: www.northlancsdirectionsgroup.com/downloads

Autism Post-diagnosis information

networkread ASC Autism pathway child diagnosis help sleep support stimming Disorder ASD not-alone assessment condition nursery carer sensoryteenageradult college school childhood parent Autisticonline community

Social Media groups and pages

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NAS Lancaster and Morecambe Branch North Lancashire Directions Group Parent Carers Lancashire Lancashire Local Offer Autism Friendly UK Piccadilly Support Services Cygnets Autism Parenting Programme





Parent Carer Information Sessions

Lune Park Neighbourhood Centre Lancaster LA1 2LN Tuesday 30th April 10.00-12.00 Tuesday 25th June 10.00-12.00 Tuesday 9th July 10.00-12.00 Westgate Neighbourhood Centre Morecambe LA4 4XF Thursday 16th May 1.00-2.30 Thursday 4th July 1.00-2.30

Have you recently received a diagnosis of Autism for your child or young person or would you just like to meet other parent carers in the same or similar situations? Would you like to talk about next steps and find out what is available to you and your family? Come along for a chat and meet with the Cygnets Programme trainer Lucy Ellis, pre-school children welcome too.

Websites

National Autistic Society www.autism.org

Lancashire County Council Local Offer <u>http://www.lancashire.gov.uk/send</u>(currently under review)

Visual aids and resources www.asdbrightideas.co.uk

For books and publications on topics including Autism and neurodiversity <u>www.jkp.com</u>

Parent-led information, resources and opinion about children and young people aged 0-25 with additional needs <u>www.specialneedsjungle.com</u>

Contact (formerly Contact A Family) www.contact.org.uk

PDA Society (pathological Demand Avoidance) www.pdasociety.org.uk

Young Minds mental health support www.youngminds.org.uk

Mind <u>www.mind.org.uk</u>

Films and videos on Autism

BBC documentary "Asperger's and Me" Chris Packham available on BBC iPlayer

YouTube film "BBC My Autism and me"

YouTube "Marvelous Max" Autism awareness for children

YouTube "What is Autism?" Video by the National Autistic Society

Books

All cats have Asperger syndrome by Kathy Hoopmann

Autism: talking about a diagnosis by Rachel Pike (NAS website)

ASD and Me. Learning about autistic spectrum disorder by Teresa DeMars

The ASD Workbook. Understanding Your Autism Spectrum Disorder by Penny Kershaw

All About Me A Step-by-Step Guide to Telling Children and Young People on the Autism Spectrum about Their Diagnosis by Andrew Miller

My Family and Me. A workbook for the family of a child with ASD. Via NAS website.

Parenting a child with Asperger syndrome: 200 tips and strategies by Brenda Boyd

How to live with autism and Asperger syndrome: Practical strategies for parents and professionals by Chris Williams and Barry wright

Asperger syndrome by Tony Atwood

Social Stories by Carol Gray

The reason I jump by Naoki Higashida

Contacts and Links

People who can help you with finding the right sources of support are:

Lancaster and Morecambe Branch of the National Autistic Society <u>www.naslandm.org</u> email landm@nas.org.uk

Lancashire County Council Children and Family Wellbeing Service.

Family Support service with bases in Lancaster and Morecambe Lune Park in Lancaster : 01524 581280

North Lancashire Directions Group Support group information for families with children with additional needs. www.northlancsdirectionsgroup.com

07873818153 (Term time only) Email <u>northlancsdirectionsgroup@gmail.com</u>

Cygnet Autism Programme (North Lancashire) www.northlancsdirectionsgroup.com/cygnets

Cygnetsnorthlancs@gmail.com

07873818153 (Term time only)

National Autistic Society www.autism.org

Lancashire County Council Local Offer

www.lancashire.gov.uk/SEND

Following Diagnosis

The important thing to remember is that your child is the same person they have always been. An Autism diagnosis can be difficult to come to terms with for some and you may experience many emotions following it. Many parents and carers can feel relieved, surprised, shocked, upset, pleased and may also go through a grieving process at any time following a diagnosis for their child or young person. Now that you know they are on the autism spectrum, you can begin to better understand their needs, arrange the right support and help them to maximise their potential.

A diagnosis can help your child to get autism-specific support, but this doesn't happen automatically.

Autism is not an intellectual disability or a mental illness. It is a neuro developmental difference, meaning as your child was developing in utero, different and often quite splendid wiring was being established. This is what allowed them to develop some of the remarkable skills that autistic people exhibit.

The following information has been put together by local parent carers and professionals.

"Autism is part of my child. It is not everything he is. My child is so much more than a diagnosis." S.L Coelho.

Further understanding

Cygnets Autism Programme

The Cygnets Programme is a FREE to access 6 week course delivered once a week for 2.5-3 hours in Neighbourhood centres in Lancaster and Morecambe which is evidence based and offers parents and carers an opportunity to learn more about Autism and how to better support their child or young person (aged 5-18) using strategies and ideas from fellow parents on the course and material from the Programme originally created by Barnardo's in conjunction with parents of children on the spectrum. This course is offered term time only at least 5 times a year for up to 12 families each time.

Areas covered by the course include Autism and Diagnosis, Communication, Sensory Needs, Understanding and Managing Behaviour.

Additional courses are available once a year on Supporting siblings to understand Autism and Puberty, Sexual Wellbeing and Relationships for young people aged 9+.

"This course has helped me to meet other parents who get it and better support my daughter." mum to 13 yr old

When should I tell my child about their diagnosis?

There isn't a 'right' way to tell your child about their diagnosis. However, here are some points to consider.

Choose a moment when you're both in a calm mood and in a familiar place where you both feel comfortable. Autistic children can find it difficult to process new information, especially if they're feeling anxious, stressed or are in an unfamiliar environment.

Try to make sure you won't be interrupted. Your child may need time to think about what you're saying or to ask questions.

One of the ways some parents start a conversation about autism is to talk first about differences. For example, you could write a list of family members' strengths and weaknesses, then talk about what your child is good at and what they find difficult. You could point out that there are many famous successful people with Autism too. Albert Einstein, Andy Warhol, Temple Grandin, Daryl Hannah, Satoshi Tajiri (Pokémon creator), Nikola Tesla, Steve Jobs, Sir Isaac Newton, Jerry Seinfield, Etc. Your child may be pleased that they now have a better understanding of themselves.

Some children will become concerned that there is something seriously wrong with them which will affect their health. You may need to emphasise that autism is not a disease, and no one can die from it. Although autism cannot be 'cured' there are ways of helping to overcome some of the difficulties your child experiences. For example, your child might have a support worker at school who helps them with tasks they find difficult. You could also point out that your child is good at some things at school which other children need help with.

Be there if your child wants to talk or ask questions. Some children may not want to ask questions face to face. Having a question box, diary or email system can make it easier for some children to ask personal questions. It also gives them more time to process your answer or think of other questions. The NAS website have some great books to help you with this process too. <u>www.autism.org</u>

"Since I found out I was Autistic aged 8, my life makes sense now and I understand why I think about things differently. It's helped me understand the world a bit more. "14yr old

Supporting your child

At school

The most important thing to say about support at school is that an Autism diagnosis does not automatically entitle your child to additional levels of support or to automatically be able to access funding.

Help at school is based on the needs of the child or young person. It is important that you should speak to your child's school or college before, during and following a diagnosis to ensure all needs are being met. Having open and frank discussions can help everyone. Never assume that all staff working with your child know about their diagnosis and understand what it means for your child.

The SENCO (Special Educational Needs Co-ordinator) is a teacher at your child's nursery or school who takes responsibility for day-to-day SEN in their setting. They will be able to talk to you, usually by appointment, about SEN and how your child's diagnosis does or does not impact on their ability to learn.

There are several organisations who can support you with sourcing the right educational support for your child or young person. See the contacts section of this booklet.

"Finding my local support group was the best thing that has happened to us. I have found support, friendship and understanding when I needed it most" Parent from Morecambe.

At home

The report from the diagnosis, if you have received one, may help you to better understand your child. Take time to read through it and make notes of any questions.

Local groups and activities

Locally there are some great groups that offer support for parent carers and children. For an up to date list please see <u>http://www.northlancsdirectionsgroup.com/downloads</u> There are many online platforms that offer support to families in the same or similar situations.

To understand the diagnosis better you can seek out support from one of the groups available locally, talking to other parents either in groups, online, on the Cygnet Programme or by contacting the professionals and services listed in this booklet.

Benefit entitlement

You may want to consider applying for additional benefits if you are not already in receipt of them. DLA (Disability Living Allowance) for children up to the age of 16 to claim call 0800 121 4600. For young people aged 16+ they will need to claim for PIP (Personal Independence Payment) by phoning 0800 917 2222 Further information on Benefit Entitlements can be found on the Contact (formerly Contact a Family) www.contact.org.uk and via the freephone number 0808 808 3555



The Lancashire SEND Partnership was formed following the Ofsted and the Care Quality Commission (CQC) joint inspection of special educational needs and disability (SEND) services in our local area.

The partnership brings together all the agencies in Lancashire which provide the SEND services for children, young people, their parents and carers. It ensures everybody can work together to provide the best outcomes for children, young people and their families, with representatives who use the service.

We will continue to share more about the changes taking place via <u>regular updates</u> so look out for notices on our <u>SEND local offer</u> website and <u>Facebook page</u> or view our event listings on <u>Eventbrite</u>.

If you would like to get in touch with the partnership team, you can email <u>SENDPartnership@lancashire.gov.uk</u> or call 01772 532 280



Scan this QR code with your smart phone camera to go to the SEND Partnership web page Parents, carers, young people and professionals have all been involved with creating the new values for the Lancashire SEND Partnership. They are:

Inclusion: Belonging and involvement Integrity: Honesty, trust and fairness Respect: Value, regard and reliability

These values will guide the way we behave towards each other and help create a culture of understanding.

Edwina Grant OBE, Chair of the SEND Partnership Board, is encouraging everyone to get behind the new independent Parent Carer Forum (PCF) as it reestablishes itself in Lancashire.

The steering-group, led by Chair Sam Jones, has been working as part of the SEND Partnership with Contact and local support groups to provide a collective voice for families of children with special educational needs and disabilities (SEND).

Parent carers interested in joining the forum can request specialist training to help develop skills in participation and co-production with a view to representing parent carers within the SEND Partnership. For more information, parent carers can email Sam Jones at Chair@lancashireparents.co.uk.



The local offer brings together information that is helpful to children and young people with special educational needs and disabilities and their families.

The special educational needs and disabilities (SEND) local offer brings together information that is helpful to children and young people aged 0-25 and their families.

You can access Lancashire's SEND local offer at <u>www.lancashire.gov.uk/send</u>.

If you don't have access to the internet you can get help to access it online at some <u>libraries</u>, <u>Children and Family</u> <u>Wellbeing Services</u> (previously children's centres) and schools.

If you'd like to receive updates from the local offer you can <u>sign up to the FIND database</u> to receive a free newsletter or <u>like us on Facebook</u>.



Scan this QR code with your smart phone camera to go to the Local Offer webpages on the Lancashire County Council Website.

Autism Hospital Passport

The aim of the hospital passport is to assist people with learning disabilities to provide hospital staff with important information about them and their health when they are admitted to hospital.

We recommend that you fill this in and return it to hospital even if you are not expecting a hospital admission. The more information Dr's, nurses, clinicians have the better. Even if you are just going for a routine appointment, having a little information on the system about the child / young person can help ease anxieties and pressures.

The hospital passport can be completed and kept at home in case of an emergency admission, deterioration in the individual's health or can be completed prior to a planned admission when it may also be used to aid assessment and planning.

An adult or child's personal details can be added to the passport by hand or on an electronic version (available below).

For further information about the passports, please contact Brian Evans, Matron for Learning Disability, Autism and complex needs, on 01229 406793.

https://www.uhmb.nhs.uk/patients-and-visitors/patientslearning-disabilities-and-complex-needs