



# NEWCASTLE PARENT, CARER FORUM NEWSLETTER



Autumn 2023

Welcome to our Autumn Newcastle Parent, Carer Forum Newsletter. We will be sharing Summer, Autumn, Winter and Spring editions to show what support is available in Newcastle and bust some myths.

Thank you for your feedback on the summer edition, we've been asked to cover a few topics in this newsletter:

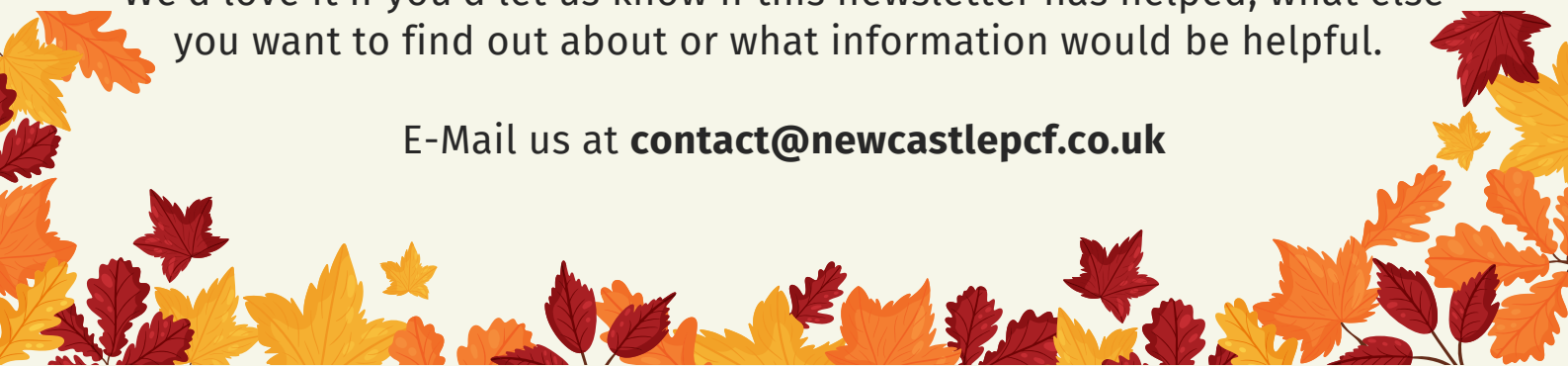
- Meet the Newcastle Parent Carer Forum
- Strategic work of the Parent, Carer Forum - Newcastle Special Educational Needs and Disabilities (SEND) Strategy and Deep Dive into Education Health and Care Plans
- Foetal alcohol spectrum disorder
- Accessing the medication melatonin
- Special Educational Needs and Disabilities (SEND) Transport Team - FAQs
- Reimagining Therapies Project

There's also things we'd like to tell you more about:

- Early identification of a learning disability - Pilot in Hadrian School
- STOMP/STAMP Survey from NHS England
- Support options from Rescare
- More information about the Getting Help and Getting More Help Teams and their role
- Teen Life Programme - Support programme for parents/carers of autistic children
- Details of Newcastle Carers Drop-Ins and Cafes
- Feedback from the waiting list survey shared in our summer edition

We'd love it if you'd let us know if this newsletter has helped, what else you want to find out about or what information would be helpful.

E-Mail us at [contact@newcastlepcf.co.uk](mailto:contact@newcastlepcf.co.uk)



## MEET THE NEWCASTLE PARENT CARER FORUM

Newcastle PCF are a steering group of parent and carer volunteers who listen to the views of other parents and carers in our community to gauge what is working, what's not working so well and to identify gaps in services. We will then liaise on a strategic level with the local authority, health and social care to work collaboratively to improve services for children and young people (0-25).

The Forum strives to support local families, sharing knowledge and advice and by helping families to come together to support each other. By being a united voice we can make sure that our children and families are at the centre of the planning and review process and are fully represented.



**ELLE MCCREADY**



**MARIE LEDDY**



**JENNY HICKEN**



**VIKKI MACDONALD**



**EVELYN CREE**



**SHONA TAYLOR**



**DEB TURNER**

# WORK OF THE PARENT CARER FORUM TEAM

## PROPOSAL FOR DEEP DIVE INTO NEWCASTLE EDUCATION, HEALTH AND CARE PLANS

The SEND Support Assessment and Review team is facing a high demand for Education, Health and Care assessments which in turn puts pressure on all parts of the education, health and care system. At the same time services are under pressure to speed up the production of advices so that more plans are completed within the 20-week timescale and meet the quality standards.

Occasionally plans are agreed where parents/carers feel that the needs of their child/young person are not set out sufficiently in the plan and appropriate provision is not put in place.

There are cases where there are concerns that needs are not appropriately reflected in the EHCP.

The proposal is to carry out regular deep dives of the plans and advices where concerns have been raised.

The aim is that the advice writers and caseworkers would come together to review the information and identify how plans could be improved. This will be a learning and supportive meeting to be conducted in line with our agreed principles about how we work and act.

We are very keen for parent/carers to attend meetings so that we can ensure your voice is heard and would welcome any feedback on how we can work together to make this possible.

## SPECIAL EDUCATIONAL NEEDS AND DISABILITIES (SEND) STRATEGY FOR LOCAL AREAS ACROSS NEWCASTLE UPON TYNE

Newcastle Parent Carer Forum has worked with Newcastle City Council and the Integrated Care Board, alongside young people with special educational needs and disabilities and parents and carers, to create the new SEND strategy.

The new SEND Strategy sets out our shared ambition in Newcastle: "To create an inclusive city that ensures that children and young people with SEND get the right support at the right time and go on to live their best lives"

The strategy was developed following a series of consultation events including focus groups and workshops held in Spring 2023. It sets out plans, for the next 5 years, to improve services and the experience of children, young people and families. You can find the strategy [here](#) and if you are a parent or carer for a child with SEND and are interested in working with us to improve lived experiences, please get in touch via:

Email: [ncleparentcarerforum@gmail.com](mailto:ncleparentcarerforum@gmail.com)

Web Page: [Here](#)

Facebook: [Here](#)

Twitter: [Here](#)

## FOETAL ALCOHOL SPECTRUM

Foetal alcohol spectrum, sometimes called FASD, results when alcohol exposure during pregnancy affects the developing brain and body of a baby. It is a neurodevelopmental condition and as it is spectrum, each person is affected differently.

**The National Organisation for FASD** provides support to people with foetal alcohol spectrum and their families and communities.

Their website has helpful information including an FAQ section covering topics like, how to go about getting a diagnosis and how it might present in people. It also myth busts common misconceptions about foetal alcohol spectrum.

## RESCARE - THE SOCIETY FOR FAMILIES OF CHILDREN AND ADULTS WITH LEARNING DISABILITIES

Rescare supports parents and carers across the UK who have loved ones with a learning disability. The services they offer are:

**Helpline** - This helpline offers advice on things like Residential care, dealing with councils, education disputes, funding, care packages and choice, legislation and more.

**Available Monday - Friday, 9am - 5pm.**

**Contact on: 0161 474 7323**

**Befriending Service** - Enabling people to feel more connected. A service designed for parents, carers, people with learning disabilities and autistic people aged 18+.

**Find out more by contacting Nicola on [nicola@rescare.org.uk](mailto:nicola@rescare.org.uk)**

**Online Zoom Forums** - They will be hosting zoom forums on topics which have arisen from talking to their members.

**Dates of future forums will be available [here](#)**

## MYTH BUSTING

**“You can tell someone has FASD because of the way they look“**

Less than 10% of people with foetal alcohol spectrum disorder will have different facial features.

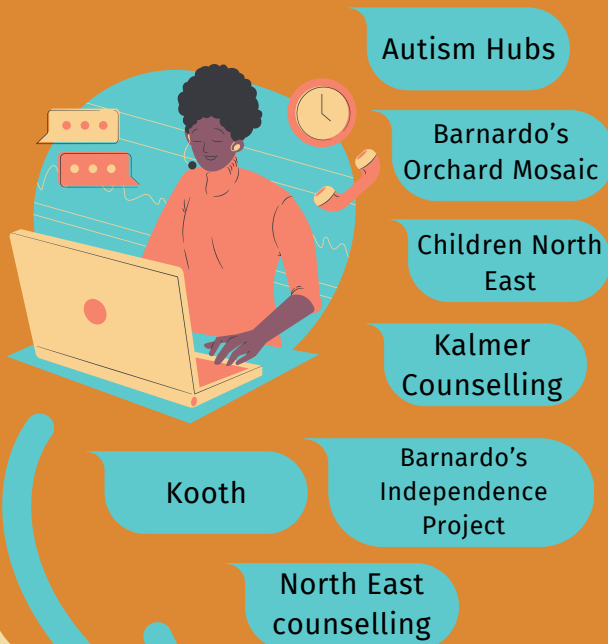
## MELATONIN (SLEEP MEDICATION) PRESCRIBING IN NEWCASTLE

The Integrated Care Board in Newcastle have become aware of difficulties that families are sometimes experiencing around the prescribing of melatonin.

The Integrated Care Board is in discussion with providers, including Cumbria Northumberland Tyne and Wear Foundation Trust (CNTW) about this and will come back to the Parent Carer Forum.



## GETTING HELP (SINGLE POINT OF ACCESS)



- Responsible for looking at the referrals that come in for mental health support and finding the best person or organisation to help.
- They might recommend support from one of the providers within the Getting Help support offer. Further details of these services can be found in our summer edition.
- They could also suggest support from organisations such as the Autism Hubs, Early Help or the mental health support teams in schools (RISE).

## GETTING MORE HELP (CYPS)

The Single Point of Access may decide a young person would benefit from assessment or intervention from the Getting More Help Service, sometimes called CYPS.

This team is not suitable for all mental health referrals but can be the right place to help when other options the Single Point of Access have suggested have been tried.



### Referrals into Getting More Help can be actioned by one of these teams

#### Learning Disability Team

This team supports children and young people, who have a learning disability and are struggling with their mental health



#### Neurodevelopmental Team

This team carry out the assessments for autism and ADHD.

They pull together information about your child from yourself, school and other professionals and decide if a diagnosis is suitable



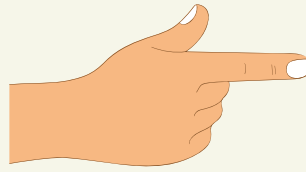
#### Mental Health Team

This team provide specialist mental health assessment and treatment for young people who have had intervention which has not helped. For example, through one of the Getting Help Providers or the Mental Health Support Teams in schools (RISE).



# THE NEURODEVELOPMENTAL PATHWAY IN GETTING MORE HELP (CYPS) EXPLAINED IN MORE DETAIL

In order to complete an assessment the Neurodevelopmental Team will capture different information about your child, some examples of how that information might be gathered are to the right (not all may be required)



- Development History
- Teacher information
- Play based/semi structured/Autism Diagnostic Observation (ADOS) Assessments
- Qb test (if required, if ADHD is suspected)
- SNAP Forms to capture current presentation
- School/Home observations
- Cognitive assessment

If your child receives an ADHD diagnosis they might require medication.

If you agree with this then a medication trial will be discussed with you.

An outcomes report and post diagnostic session your child will be discharged or transferred to the clinic for medication titration.

If your child receives an autism diagnosis CYPS will provide information about services that can support you and your family e.g. Autism Hubs (see below).

CYPS does not provide post-diagnostic support.

If your child does not receive an autism diagnosis you will be signposted to the most appropriate service.

## SUPPORT WHILE YOU WAIT

There are autism hubs in Newcastle for parents/carers of children (0-18) who are waiting for an autism assessment or have a diagnosis of autism. They run webinars and workshops on topics like sensory needs, sleep, toileting and behaviours that challenge.

The sessions are held in the 4 locality hubs in Newcastle.

**Nunsmoor Centre** - 1st Wed of the month

**Galafield Centre** - 2nd Wed of the month

**Byker Sands** - 3rd Wed of the month

**Fawdon Community Building** - 4th Wed of the month

You can find more information, and the contact info to book a place [here](#)



# THE MENTAL HEALTH PATHWAY IN GETTING MORE HELP (CYPS) EXPLAINED IN MORE DETAIL

**Who is this service for:** Children who have moderate to severe mental health problems. This would usually mean the child or young person's mental health is really impacting on their ability to function and/or their presentation/needs are complex and likely to require longer term **specialist** clinical intervention/support.

Whilst we know that issues such as bereavement, sadness, worry and anxiety can impact on wellbeing and resilience CYPS would not usually expect to see a first time referral into Getting More Help services for this alone. A referral would usually be more appropriate for the Getting Help Services. In addition if a young person has risky behaviours this does not automatically mean they have a moderate to severe mental health problem. In this event advice can be sought from the Single Point of Access.

In your first appointment these are the things you might discuss:

- Reasons for referral
- Young person's feeling about referral and reasons for it
- Difficulties the young person is experiencing
- How the service can support and what goals would be helpful

The service will look for the right clinician with the right skills to work with the young person to discuss treatment and intervention options and agree a treatment plan.

This plan will include:

- How often you'll be seen
- How many sessions you'll have
- What will be covered in each session

The goals set in the plan will be discussed regularly to see how much progress is being made.

If medication is suggested as a way of supporting, the Psychiatrist or Nurse will discuss the options available.



## EARLY IDENTIFICATION OF LEARNING DISABILITY FOR CHILDREN AND YOUNG PEOPLE

A pilot has begun in Hadrian Specialist School regarding the early identification of a learning disability in childhood (this is not a diagnosis)

From September 2023 for new students, Hadrian School is using the Education Health and Care Plan (EHCP) review to discuss whether it is more likely than not that a child has a learning disability, with their parents/carers. If agreed this will be written in the EHCP.

In addition, with family's consent the child's GP Practice will be contacted to add them to the practice's learning disability register. This will enable them to access an annual health check once they turn 14 and discuss reasonable adjustments with their practice.

This decision will be discussed and reviewed as part of their year 9 annual review if the child goes on to attend Sir Charles Parsons.



## WAITING FOR AN ASSESSMENT OR TREATMENT WITH A HEALTH SERVICE

In July 2023, we ran a survey to find out what support parents/carers had been offered whilst waiting for an assessment or treatment. The results on the survey have been reviewed and you can view the outcome report and actions we plan to take [here](#) (in the "Parenting support and New Parent Advice" header).

## NEWCASTLE SENDIASS

**SENDIASS** are a service that can help you know your rights, access services you need and they can participate in school discussions with you.

You can contact Newcastle SENDIASS via phone or e-mail using the details below:

Phone - **0191 211 6255** - From 9am - 5pm

E-Mail -

**SENDIASSadmin@Newcastle.gov.uk**

## MYTH BUSTING

**"My child needs a diagnosis to get the support they need at school"**

Your child does not need a diagnosis to receive support at school.

You also don't need a diagnosis to receive support through an Education Health and Care Plan.



## ARTS CONNECT TEAM

The team meet with children with special educational needs and disabilities in Newcastle and help them to get connected with arts groups, workshops and artists. Referrals come from the Children with disabilities team, school, parents and young people.

**Hang out and dance at Dance City** - Dance and aerial sessions in a small group with a high staff ratio. First session is free and following bookings are £5. They run one Sunday per month and bookings can be made through **Dance City on 0191 261 0505**.

**Konnect Music** - A free digital music making group for young people aged 10-18. The group make a track each time they meet and upload it to bandcamp. Sign up and see more information [here](#).

**Family Photo Club** - Inclusive family photo club using iPads to create visual art. It's free to come along and the group meet the second Saturday of the month at the Newcastle City Library.

**Art, music and movement garden** - A relaxed family session at Scotswood Garden to create nature inspired art using a range of materials found in the garden or explore sound, rhythm and movement. Visits are free and bookable for each Saturday through **Sally Southern on 07808473300**.

**Saturday art classes** - Art classes for young people 10-15, held on the first Saturday of the month at the Laing Art Gallery. To book or for any queries contact [learning@laingartgallery.org.uk](mailto:learning@laingartgallery.org.uk)

## MYTH BUSTING

**“The RVI closes their autism assessment waiting list at Easter and ask for referrals to be made to CNTW in September”**

The waiting list remains open and active through the year. However, as it's a pre school autism service, referrals for children who will be starting school in September will be deferred to the children and young people's service (CYPS)



## MYTH BUSTING

**“If my child is transferred from the RVI to CNTW autism waiting list, they will go to the bottom of the queue”**

The original referral date is honoured by CNTW. If a mistake is made it will be rectified, you just have to let CNTW know.

## THE CARERS WELLBEING FUND

A grant from the Carers Wellbeing Fund can be used to give you a break, support you in your caring role, and/or maintain or improve your health and wellbeing.

The funding is provided by Newcastle City Council and the North East and Cumbria Integrated Care Board (NHS) and is administered by Newcastle Carers.

You can apply to the Carers Wellbeing Fund if you are over 18 and look after someone, (and are not employed to do this), who is ill, disabled, has mental health problems or an addiction to drugs or alcohol, who could not manage without your help.

You can find out more about the fund and download an application pack [here](#).

## NEWCASTLE CARERS DROP IN SESSIONS

Newcastle Carers run local drop in sessions to provide information and support to help find ways to manage your caring situation.

**Gosforth Library, Regent Farm Road, Newcastle, NE3 3HD**

Every Monday from 10am - 12 noon

**Newcastle Carers, 135 - 139 Shields Road, Byker, NE6 1DN**

Every Tuesday & Friday from 1pm - 3pm

**Cruddas Park GP Surgery, 178 Westmorland Road, Newcastle, NE4 7JT**

Every Wednesday from 1:30pm - 3:30pm

**Westerhope Community Association, Hillhead Road, Newcastle, NE5 1NE**

Every Thursday 10am - 12 noon

## WESTERHOPE CARERS' CAFE

On the last Thursday of every month there is a Carer's Cafe running 10:30am - 12noon at **Westerhope Community Association ("The Tute")**, Hillhead Road, Newcastle Upon Tyne, NE5 1NE.

Hosted by Newcastle Carers it's a chance for people to take a break and connect with other carers.

You can find out more by calling their Carers Information Line on **0191 275 5060**  
Monday - Friday, 10am - 4pm



## YOUNG CARER'S ANIMATION PROJECT #WECARETOO

Young carers from across the city of Newcastle have developed four animated films to raise awareness about young carers and highlight the issues faced by young carers. You can view them [here](#)

## YOUNG CARERS GROUP SUPPORT

Newcastle Carers have 2 young carers support groups, one for children aged 8-11 years old and one for 11-16 year olds.

They usually take place during school term time and activities are provided free of charge.

If you'd like to find out more you can get in touch with Newcastle Carers [here](#).

## TRANSFORMATION OF PEADIATRIC THERAPY SERVICES (SALT, OT, PHYSIO)

The ICB are working with Newcastle Hospital Trust (RVI), CNTW and the Local Authority to determine what therapy services need to look like, to meet the needs of children and families in Newcastle.

Areas being looked at:

- An online referral system.
- Universal, targeted and specialist offers according to need.
- Reduction in waiting times.

The first pathway to be redesigned is the adaptations pathway which is occurring in October 23.

Further key pathways may be reviewed in each of the therapy services.

### TEEN LIFE - PARENT/CARER SUPPORT INTERVENTION FOR AUTISTIC CHILDREN

Run by the Educational Psychology Service, Teen Life is a 6 week programme, licenced by the National Autistic Society, designed for parents/carers of autistic young people aged 10 - 16.

The weekly sessions cover a range of topics including;

- **Stress and Anxiety**
- **Understanding Behaviour**
- **Autism in Women and Girls**
- **Puberty**
- **Independence Skills**
- **Planning for the Future**

The small groups allow for personalised discussion and support and each family, if they so wish, can nominate a supporting professional to attend alongside them. This could be a member of staff from their school, presenting the opportunity to develop a shared understanding.

For any queries or an application form for the programme e-mail [teenlife@newcastle.gov.uk](mailto:teenlife@newcastle.gov.uk)



### STOMP / STAMP SURVEY - NHS ENGLAND

**STOMP** - Stopping The Over-Medication of People with a learning disability, autism or both.

**STAMP** - Supporting Treatment and Appropriate Medication in Paediatrics

The NHS England STOMP and STAMP team along with Learning Disability England and Challenging Behaviour Foundation want to stop psychotropic medication being used for the wrong reasons for autistic people and people with a learning disability.

They would like to capture the thoughts of autistic people, people with a learning disability, families and carers through the survey they have developed, [here](#).

## CO-DEVELOPED SHORT FILMS - GP LEARNING DISABILITY REGISTERS AND EDUCATION HEALTH & CARE PLANS

2 new short films have been added to the Learning Disability Matters for Families website.

The first is around understanding the GP learning disability register, annual health checks and reasonable adjustments.

The second is understanding what Education, Health & Care Plans are and the experiences from young people who have them.

**GP Learning Disability registers - [Video Here](#)**

**Education Health & Care Plans - [Video Here](#)**

## FAMILY ADVICE AND SUPPORT TEAM - SKILLS FOR PEOPLE

Skills for People have a Family Advice and Support Team who work with parents and carers of disabled children and young people up to the age of 25.

They can help with things like how to navigate the local offer, connecting you with other support services and they can offer advice on specific issues such as transport, holidays, activities and planning for adulthood.

The team run coffee mornings and drop ins in Newcastle, giving parents and carers the chance to meet one another and find out what works for other families in Newcastle. You can keep up to date with when these will be held by joining the Pass it on Parents Facebook page [here](#).



## BONFIRE NIGHT CELEBRATION - HADRIAN SCHOOL

Hadrian School is hosting a Bonfire Night celebration on 10th November at 5pm.

Enjoy a night of fireworks, food and fun!

Tickets are £3 and can be purchased at Hadrian School Reception.

**Hadrian School, Bertram Crescent, Newcastle, NE15 6PY**  
**[hadrian.newcastle.sch.uk](http://hadrian.newcastle.sch.uk)**

## SUPPORT WHILE ON THE CNTW AUTISM ASSESSMENT WAITING LIST

If confirmed your child is on the waiting list for an Autism assessment with the Children and Young People's Service, they run workshops to offer support while you wait.

Workshops offering support with sleep and executive functioning skills (working memory, cognitive flexibility and inhibitory control) can be booked through emailing **[NGCYPWelcomeEvent@cntw.nhs.uk](mailto:NGCYPWelcomeEvent@cntw.nhs.uk)** or contacting the **Duty Team on 0800 652 2864**.



## SEND TRANSPORT SERVICE - FREQUENTLY ASKED QUESTIONS

The Local Authority SEND Transport Service has collated their most frequently asked questions to help give families a better understanding of what the service does and does not do.

If after reading this you're still unsure of anything, the team can be reached on 0191 277 4646 between 7:30am - 4:30pm.

You can also access their Parent Carer Hand Book [here](#). The handbook includes more detailed information about their published criteria, how to apply and more about what to expect from the service.

### MY CHILD HAS AN EDUCATION HEALTH AND CARE PLAN (EHCP) IN PLACE, DO THEY AUTOMATICALLY QUALIFY FOR SEND TRANSPORT?

The pupil's individual needs will determine their entitlement, rather than whether an EHCP is in place. An EHCP, or attendance at a specialist school or Additionally Resourced Provision (ARP) does not guarantee travel or transport assistance.

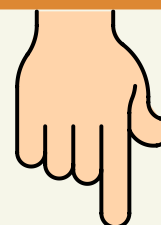
Parents have a right in law to state a preference for a school for their children, but that does not carry with it a right to free transport.

You can view the published criteria [here](#).

### IF MY CHILD HAS SPECIAL EDUCATION NEEDS, WILL THEY NEED TO BE TAKEN TO SCHOOL BY SEND TRANSPORT?

No, if your child is eligible for SEND Transport, they will also qualify for a Personal Travel Budget which allows for more flexibility.

See more on Personal Travel Budgets below.



**Personal Travel Budgets** allow families to arrange their child's home to school travel arrangements in a way that suits them. It's a flexible resource which allows for your child to attend more extra-curricular activities and increase their life skills.

Travel amounts per mile are on a scale according to your child's need, starting at 40p and moving up to 70p and over 70p to cover exceptional need.

You are able to claim for 4 journeys per day to and from school which can be used in creative ways such as contributing towards;

- Buying a travel pass for an adult to accompany your child to and from school.
- Paying for a travel escort to walk with your child to school.
- Assist with the cost of driving or cycling with your child to school.
- Share travel arrangements to other parents.
- Assist with the cost of childcare arrangements for siblings to allow parents to take their child to school.

**ONCE SEND TRANSPORT HAS BEEN PUT INTO PLACE, WILL MY CHILD REMAIN ON TRANSPORT FOR THE REST OF THEIR SCHOOL LIFE, WITHOUT RE-APPLYING?**

No, you will need to complete an application form each year. You will also need to complete a new application form if any personal circumstances change i.e. if you move home or school to ensure the information we hold is up to date and relevant.

If your child is remaining at their current school for the next academic year, or you know which school they will be transferring to we will need you to submit application forms by the end of the Spring term (Easter Holidays).

**DOES SEND TRANSPORT PROVIDE CAR SEATS?**

No, this would need to be provided and fitted by the parent or carer.

**WILL THE ESCORT OR DRIVER KNOCK ON THE DOOR FOR MY CHILD AND WILL THEY DROP THEM OFF AT THE DOOR ON THEIR RETURN HOME.**

No, it is the parents' responsibility to make sure the child is safely on the vehicle and that they are collected from the vehicle on their return journey. If no one appears to collect your child after 3 minutes, the driver / travel escort will notify the SEND Transport team. If we are unable to contact parent / carer, or the emergency contact provided by you, we will contact children's social care who will determine appropriate action.

**HOW DO I KNOW IT'S SAFE TO ALLOW MY CHILD TO TRAVEL WITH SOMEONE THEY HAVEN'T MET BEFORE? DOES THE TAXI JUST TURN UP ON THE FIRST DAY OF SCHOOL TERM?**

No, before a route begins, the provider will contact you to arrange to meet you and your child. If you do not hear from the transport provider, you should phone the SEND Transport Team. A time and start date for your child's transport will always be arranged in advance.

**HOW LONG WILL THE TRANSPORT WAIT IN THE MORNING?**

Transport can only wait for 3 minutes otherwise it will make the vehicle late for other children on the route.

**IF MY CHILD NEEDS A HARNESS TO TRAVEL SAFELY, DO I NEED TO PROVIDE THIS?**

This will be provided by the SEND transport service. These are returned to us when a child either no longer requires it, has outgrown it or moves route. They are also returned to us at the end of the summer term so that we can ensure that they are in good order, and we replace any that are showing signs of wear.

**You can read the SEND Transport Post 16 Transport Statement 2023/24 [Here](#)**

