

# NYPACT news

The collective voice for parents and carers in North Yorkshire



Welcome to NYPACT News, your newsletter from North Yorkshire parent carer forum. NYPACT is a non-profit making organisation run by parents for parents.

## Supporting parent carers

**Being the parent of a child with additional needs or disabilities can be greatly rewarding! But it can also be very hard work.**

There may be times when there is just too much to do; not enough money coming in or time for a social life; not enough sleep or time for relaxation. You may experience frustration when trying to navigate the 'Red Tape' of authority. Sometimes we all need a little extra support and encouragement; and sometimes we need practical advice and guidance.



Staff, trustees and volunteers at Scarborough & Ryedale Carers Resource



Staff, trustees and volunteers at Hambleton and Richmond Carers Centre

This is where Scarborough and Ryedale Carers Resource and Hambleton and Richmondshire Carers Centre can help. We support unpaid family carers from ages 8 upwards. We have dedicated services for Young Carers (aged 8-16), Young Adult Carers (aged 16-35) and an Adult Carers service for those 35+. Because of our partnership, we can support carers in areas across Scarborough, Whitby and Ryedale as well as in Hambleton and Richmondshire.

Because of our partnership work, we can support carers in areas across Scarborough, Whitby and Ryedale as well as the Hambleton and Richmondshire areas.

We focus on YOU and can help reduce the stress of caring by:

- Giving impartial information and advice
- Providing emotional support & time to talk
- Guiding you through the 'Red Tape' of authority
- Helping to maximise your income
- Signposting to appropriate services
- Providing information and practical support with training, volunteering & employment
- Giving you an opportunity to meet other carers at events & social outings

If you would like to find out more about our services, please contact Scarborough & Ryedale Carers Resource on **01723 850155** if you live in Scarborough, Whitby or Ryedale or call **01609 780872** if you live in Hambleton and Richmond. Further information is also available on our websites: [www.carersresource.net](http://www.carersresource.net) and [www.hrcarers.org.uk](http://www.hrcarers.org.uk)

**We are here to support YOU!**

# Multisports

Fun sports based coaching for children who have special educational needs or disabilities.

Try a range of different sports including football, hockey, cricket and more.  
**Open to children aged 5 - 12 years.**

**Knaresborough Community centre**  
**Wednesdays 5-6 pm**

**Ripon Leisure Centre**  
**Thursdays 5-6pm**

**£6 per session**  
(payable half termly in advance)

**Harrogate**  
BOROUGH COUNCIL

For further information or to book your place, please contact Dannie Mulholland on 07525 988145 or email [sports.development@harrogate.gov.uk](mailto:sports.development@harrogate.gov.uk)



## Boroughbridge Juniors FC - Ability for All team

**Boys and girls of any ability are welcome to come along and join in Boroughbridge JFC's fun, friendly sessions.**

They are held fortnightly on a Sunday morning during the season at Boroughbridge Football Club or indoors depending on conditions. Each 60-minute session is delivered to help children enjoy and take part in a fun, friendly environment, with the aim of helping them develop their football and social skills. They help in every aspect of the club.

Friendly games are also organised against teams of similar ability within the West Riding County Football Association area. This year our team competed in tournaments against other Ability for All teams and really enjoyed the experience. Anyone interested please contact Chris on **07764 775130**.

Boroughbridge Junior FC serves the local community and surrounding villages. We are an FA Charter Standard Club which is a kitemark awarded to football clubs that provide a high quality football experience. FA Charter Standard Clubs are

proven to be well-run, sustainable and importantly place child protection, quality coaching and safety as paramount. The club is affiliated to the West Riding County Football Association.

To find out more visit [www.boroughbridgejuniorsfc.co.uk](http://www.boroughbridgejuniorsfc.co.uk) or search for Boroughbridge Juniors FC on Facebook. We also have a Twitter account [@BbridgeJFC](https://twitter.com/BbridgeJFC) featuring news from the club or email [bjfc2014@gmail.com](mailto:bjfc2014@gmail.com)



# Mencap, Northallerton

Northallerton and the Dales Mencap Society now has a new enlarged facility which has been renamed the Goosecroft Centre.

The refurbished facility includes an enlarged kitchen used for training and for catering, an additional interview/office space and a small multi-purpose room. There is WiFi access and a large smart TV in the main meeting area. There is a new office for Mencap and additional storage. The design also includes a spacious up-to-date Changing Places toilet which includes a hoist and adjustable height changing bench and wash basin.

The centre runs a very successful range of activities for people 18+ at the Wednesday weekly drop-in, including sports with Joe McKechnie, karaoke, a 'guess-what?' quiz, making and taking and much more. Activities run from 1.30pm – 2.30pm after the weekly drop-in and café. Sue Coulson and several volunteer helpers organise the café and serve healthy lunches and very popular cake tray bakes. Everyone is welcome to come to the drop-in to meet friends, socialise, play games and enjoy music or an activity of your choice.

Cookery classes are fun and offer the chance to learn skills to make healthy lunches that people can try at home.

POSCH parent carer support group now has monthly meetings at the centre; the next is Thursday 17th May from 10am.

An iPad club has started on Friday mornings from 10am-12pm offering the chance to learn how to use your iPad and be safe while doing so. People can join to learn the very basic skills or develop skills they already have. We have some iPads to use or you can bring your own. If you want to know more or you want to book a place on a course please contact: **Sue Lear Tel: 01609 778894** or email: **admin@northallertonmencap.org.uk**



## POSCH parent support group meetings – new venues

**There is nothing like talking to a parent who is going through a similar situation to yourself.**

POSCH are Parent/carers Of Special Children who believe in collective empowerment & partnerships to support, improve and inspire better outcomes for children and their families.

Recently becoming a registered charity, POSCH currently run carers support groups in Northallerton, Bedale, Colburn & Stokesley. In addition to group support POSCH offers phone, messaging and one to one support for carers in our local community.

POSCH is parent/carer led by volunteers who support families who have children with any additional needs, with or without diagnosis.

[facebook.com/poschsupport](https://facebook.com/poschsupport)  
[www.posch.org.uk](http://www.posch.org.uk)

**Thursday 21st June**  
West Green Deli, Stokesley – 10am





## Hello, my name is Henry. I have Dyspraxia, Dyslexia and Visual Eye Disturbance

Mummy is typing this for me as I say the words I would like to be said. If I wrote them down it would take ages for me to do it on paper!

It is hard to explain what it is like. I think I was about 8 when I realised other people were always doing things easier than I could. I did not know what to do. Mummy had taken me to the hospital in Harrogate to see a children's doctor. I then saw a lady called Nikki who helped me with movement and she came into school and helped my teachers think of ideas to help me. School had already got me a writing slope, but we looked at some new ideas. Some days ideas work and others I could be back in a muddle. Mum says Nikki was an Occupational Therapist.

I know a lot of facts, especially about space, animals and rugby but when it comes to writing it down it is weird because I know the answers or information I want to write but my brain will not let my hands write it or gets it jumbled before the paper. It is like been super tired and I cannot work it out.

Sometimes Dyspraxia is annoying, but I do get extra help in school which is good. Some of the good stuff about Dyspraxia is that I got to go on a

Special Trip to London with mummy because we went to help the research into my Dyspraxia at Great Ormond Street Hospital. I did some walking, hopping and went in an MRI machine so they could look at my brain to compare with children with no Dyspraxia. I was helping new doctors learn!

For a long time whenever I read the words they would move on the page in waves, numbers jumped about so it was hard to learn. It was not until I was a bit bigger that I realised they were not meant to do this, so I told my family. I got another appointment at the hospital with Nikki and had to do lots of reading and looking at shapes. The lady was helpful and told me it wasn't me it was my eyes and I had something called Visual Eye Disturbance. I then got some blue overlays and it helped, it was amazing the colour helped but I kept dropping them or forgetting where I had put them. So Mummy took me to a special glasses place, I now have some blue glasses and the blue helps the words from moving around. The bad news is - I am not keen on wearing my glasses because some people stare at me and that makes me feel uncomfortable. I can also use blue paper instead as that does help and no one can see the glasses then.

I get anxious about standing up at assemblies or on stage. I get sad because if I wear my blue glasses I worry about people staring at me but if I don't the words sometimes can move on blue paper, so I get stressed that I may get the speech wrong and then people may laugh at me.

I also get sad in Maths, because I am in the lowest group. I need help in literacy circles and maths. All my best friends are in higher groups so all the time I think it is not fair. The good news is just recently I have started understanding maths a lot more, I did not feel as tight and stressed in my maths lessons this term.

My family and friends tell me I have so much more, they are nice and say I am so kind and helpful. I have begun to realise now that I am eleven I need to face Dyspraxia like a rugby match and I cannot let it win, so this Easter for the first time I am going to stand up and do a full reading. I have read the odd sentence before but not one as long as I will be doing tomorrow. I am very proud to just make the decision to stand up in front of people.

I love sport, sometimes I still lose my balance and drop the ball. I worry that the other players will feel let down at rugby if I drop the ball. In sport I have surprised everyone and shown I can run fast and I have practiced so hard with my balance. I have played well in team sports and rugby. I have

made it into Sporting Start's Gifted and Talented. This moment was the best in my life, I have forever seen other children do so well in school work and I struggle, my teachers do encourage me and reward with head teachers awards for my efforts and that makes me smile. Getting into Gifted and Talented I did all by myself and was selected by Sporting Start. Kate and Claire from Sporting Start help me feel more confident. I feel so happy watching or playing sport as this is my time. It helps me forget my worries about school and what I cannot do.

I am moving up to big school in September and I am excited and worried but then I guess my friends are as well. I am worried that people will laugh at me not been able to do anything. When I was little it never used to worry me, but it does at times, so I get cross when I get home as it is unfair. I am very lucky though and I have a lot of friends. Mummy tells me how important this and I know I will always have these friends. Also, the High School said I will be able to use an iPad or laptop more than Primary School, this is brilliant because life is so much easier on a screen.

I love to play games such as Minecraft on an iPad at home. I can easily message my friends because the text changes for me and helps. Mum says this is called predictive text.

It is tough having Dyspraxia, I have had quite a lot of falls, staircases are hard work and I have been to A&E quite a few times! BUT I can run, I can spend time with friends and family, I can play lots of sports, I did have to keep practising but I did it. I can go out around the village with my friends, I can use computers, so I know I am very lucky. No matter what makes things hard, you just must keep going and then you can join things like Sporting Start like me and begin to understand maths or stand up on a stage!

In meeting me until I write or fall you would never know I have Dyspraxia. I still find it difficult to tell anyone I am struggling or that I am feeling tight or sad. I always can tell my parents and close friends. I would advise that you do not pretend you can do something as then you may get some more help.

**I hope your journey gets help like mine.**

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**“It is tough having Dyspraxia... BUT I can run, I can spend time with friends and family, [and] I can play lots of sports.”**

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## Contact – the national charity supporting parents of disabled children

### CONTACTING OUR HELPLINE

**Freephone: 0808 808 3555**

9.30am-5pm, Monday-Friday; free from UK landlines and UK mobiles

### HOW OUR HELPLINE CAN HELP YOU

We understand that life with a disabled child often brings unique challenges. Our helpline advisers can help you feel more confident and informed about tackling them.

**We can give you advice, information and support about any concern or question you might have, including:**

#### Getting a diagnosis and medical information

We can help you get a diagnosis for your child. We also have reliable and trusted information on hundreds of conditions, including rare conditions. If you want, we'll put you in touch with national and local condition support groups and introduce you to our online community, where you can chat with families across the UK affected by the same condition.

#### Services your family might be entitled to

We'll help you to understand how to ask the local authority for practical help and support for your family.

#### Benefits and sources of financial help

Find out what benefits you might be entitled to and other potential sources of financial help.

#### Support in the early years

We can tell you more about your rights to childcare and how to find childcare places in your area.

#### Special educational needs

If you think your child might have special educational needs (SEN) and needs extra help in the classroom, we can help you understand more about how special educational needs are identified and assessed, who is responsible for providing help for your child at school or college and how to access support for them there.

# YES @ Richmond School

YES @ Richmond School has been created to support schools in the development of high quality provision to meet the needs of children and young people with Specific Learning Difficulties.

## Our aims:

- **The early identification of children and young people's needs and early intervention to support them**
- **Inclusive practice and removing barriers to learning**
- **Provide high quality training to enable schools and parents to improve the outcomes for children and young people.**

Training covering all areas of Specific Learning Difficulties will be available at Richmond School throughout the year.

Listings of planned training is constantly updated on our website.

## Specialist Website

The YES @ Richmond School website school provides you with:

- **Updates about education research linked to Specific Learning Difficulties as they become available during the academic year**
- **Resources from training we provide / host**
- **Signposting to local and national support for students with additional needs**
- **Classroom resources**
- **Specific intervention resources**

[www.yesatrichmondschool.net](http://www.yesatrichmondschool.net)

## Upcoming Training Events

**22nd June 2018**

*A Child Centred Approach – The Importance of Understanding Neurodiversity*

**29th June 2018**

*Assistive Technology Showcase*

**19th October 2018**

*Examination Access Arrangements for General Qualifications*

**23rd November 2018**

*Poor Attention & Concentration – Is it a Sensory Issue?*

## Are you in a rural area looking for support to find a job?

Our supporting you to work scheme acknowledges the difficulty some disabled people may have accessing employment support in rural areas. We can help by providing support online using Skype. Don't worry if Skype is not your thing; you can also access our service via email or telephone.

We will provide each eligible person with their own employment advisor to support and guide them as appropriate.

### Our aim is to:

- Provide support from an employment advisor/job coach to look at employability skills
- Provide support seeking out opportunities that match skills
- Provide resources to help with CV and interview techniques
- Provide support and guidance for up to 12 weeks and no less than 12 hours

The service is open to disabled people who:

- ✓ Live in North Yorkshire
- ✓ Are of working age
- ✓ Are looking for paid employment
- ✓ Have access to a telephone and an internet enabled device

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



Disability Action Yorkshire



@disactyorks

Charity No: 1044373

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yorkshire YEARS

# SWAN

## Does your child have global developmental delay (GDD) or learning/physical difficulties that are unexplained?

**Has your child had genetic tests that have come back negative or with results of 'unknown clinical significance'? Are they taking part in, or are you hoping to take part in, genetic research studies such as Deciphering Developmental Disorders (DDD) or 100,000 Genomes Project?**

Hi, I'm Lisa, I am the SWAN UK parent representative for North Yorkshire and if you answered yes to any or all of the above questions then you should join our local SWAN UK community! Membership is free so email: [joinus@undiagnosed.org.uk](mailto:joinus@undiagnosed.org.uk) to find out more.

SWAN stands for syndromes without a name and SWAN UK is the only dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK. We are run by the charity Genetic Alliance UK.

Back in spring 2016 I wrote an article for the NYPACT newsletter explaining what SWAN UK does and how we provide support. If you would like to take a look at that, please do so

[www.nypact.org.uk/images/nypactnews/Spring%202016.pdf](http://www.nypact.org.uk/images/nypactnews/Spring%202016.pdf)

Here at SWAN UK we have a Big Ambition – we want every family affected by a syndrome without a name to get the support they need, when they need it, regardless of whether they have a diagnosis or not. We also want it recognised that being undiagnosed is not always a temporary stage, the genetic cause of some conditions may never be known and this can be a very lonely place for families. I know many families who, before

they found SWAN UK, genuinely thought they were the only ones in this situation. Actually around 50% of children and young people currently having genetic testing through the NHS won't get a confirmed diagnosis.

Our SWAN UK Local Networks have been popping up all over the country to provide representation and support to affected families at a local level. This has given many parents and carers the opportunity to meet up in person for a coffee, (there seems to be an overwhelming correlation between coffee and being a SWAN parent, largely due to the fact so many of our children have sleep issues for one reason or another I suspect!) and have a chat with other people who understand how hard not having a diagnosis or any answers can be. We also organise family days out and activities such as stay and play activities in accessible venues.

Fellow SWAN UK Parent Reps like myself work regularly with professionals in the local medical and SEN community and attend workshops/events/meetings to promote the opportunities that being a part of SWAN UK, both as a regional member and in the wider group, can provide. We also liaise with and invite local politicians to learn more about being undiagnosed and how it

affects their constituents so they have a better understanding of their communities' needs.

There are many up and coming important events that SWAN UK will be a part of during 2018. By the time this article has been published, Rare Disease Day 2018 will have taken place on 28 February. This annual event aims to raise awareness among the general public and decision makers such as politicians about the impact of living with a rare disease and the impact both on patients and their families.

Our celebration for Undiagnosed Children's Day will take place on Friday 27 April 2018. As well as various exciting activities/outings for the whole family, the week leading up to this and beyond will be full of marvellous pictures, blogs and information about how SWAN UK and the Local Networks can help you, so please do take time to get in touch. We will also be holding an information stand in Harrogate & District Hospital on 27 April so pop in and see us!

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**If you would like more information on our activities in North Yorkshire please email me -**

[northyorkshire@undiagnosed.org.uk](mailto:northyorkshire@undiagnosed.org.uk)



# Inclusion Conference

## 'Let's Communicate Together 2018'

supporting children and young people's  
communication and interaction needs

This event has been co-produced by NYPACT (North Yorkshire Parent and Carer Forum) and the Inclusion Service to support children and young people with SEND, their families, and schools or settings.

The day will be made up of: keynote presentations from Jean Gross CBE and former national Communication Champion, from Anna Branagan of 'Word Aware', and from young people, as well as wide variety of workshops such as play therapy, whole school approaches to SLCN and to autism, joining up 'Early Journey' support from a NYPACT parent, drama therapy, support at early years, strategies for children and young people who are demand avoidant, screening for SLCN amongst others. There will also be opportunity to browse information stands and to experience the delight of The Forest School signing choir.

## The Pavilions of Harrogate, Friday 22nd June 2018

- Free event for parents and carers
- Buffet lunch included,
- Specialist crèche onsite – pre-booking required
- Reasonable childcare and travel costs can be reimbursed

To book log onto Eventbrite –  
[lets-communicate-together-2018.eventbrite.co.uk](http://lets-communicate-together-2018.eventbrite.co.uk)

## Max Card

You can now use your max card at exciting new venues in North Yorkshire! We have some new venues that have joined us here at Max Card that will make for an educational and fun family day out.

### Butlin's

Yes! Butlin's is here! Max Card users can enjoy access to Butlin's Privilege Holiday Club plus an extra £20 off their holiday across the three sites; Bognor Regis, Minehead or Skegness ! Just in time for summer!

### Richard III & Henry VII Experiences

Discover the story of medieval York during the reign of Richard III through to King Henry VII for FREE with your Max Card

If you haven't received your max card yet please contact NYPACT:

email: [NYPACT@communityfirstyorkshire.org.uk](mailto:NYPACT@communityfirstyorkshire.org.uk)

or on: telephone: 01904 704177

We are now working with over 50% of local authorities across England and have more than 1100 attractions to visit and enjoy!



## Contact us...

### North Yorkshire PACT

Unit A, Tower House, Askham Fields Lane,  
Askham Bryan, YORK, YO23 3FS

Telephone: 01904 704177

Website: [www.nypact.org.uk](http://www.nypact.org.uk)

Email: [NYPACT@communityfirstyorkshire.org.uk](mailto:NYPACT@communityfirstyorkshire.org.uk)

Facebook: [www.facebook.com/NYPACT](http://www.facebook.com/NYPACT)