



## **Downright Special Update – March 2023**

Welcome to our latest update! The aim of these half termly newsletters is to keep Downright Special families up to date with what is going on in Friday Group sessions, term dates, training courses, social and fundraising events, as well as health and education news.

## **Down Syndrome Awareness Week 20<sup>th</sup> - 26<sup>th</sup> March**

---

We have to begin this newsletter with a massive **“THANK YOU”** to you everyone for getting involved in World Down Syndrome Day and Down Syndrome Awareness Week.

So far, we think we have raised around £4000 but there is still more to come in. We will let you know the final total as soon as we have it!

Special mention must go to:

- Everyone who got involved in the Downright Special/First Touch FC charity football match organised by Lisa Bloomer, Karl Southwick and Kerli Southwick. Thank you to the players, sponsors, venue, supporters, volunteers, and everyone who donated to the Just Giving Page
- The Little Yorkshire Dance Academy / Joanna Harker who organised ten local dance schools to ‘dance their odd socks off’ in awareness week.
- Louise Smith for organising another very successful Downright Special Awareness Week Pop-Up Café. Loads of families and friends of the charity came along to enjoy the cake, craft activities and entertainment from the Sunshine Strummers.
- All those who organised bake sales including Jennie and Emma Smith and Kirk Ella Primary School. We’re sure there are more too that we don’t yet know about!
- Newland School who organised ‘Newland’s Greatest Dancer’ competition
- Everyone who organised a coffee morning, including Eastfield Primary School
- Everyone who wore their #LotsOfSocks to raise awareness, including the schools and businesses who took part.
- All those who set up a Facebook Fundraiser, or added a ‘Donate’ button to their posts or who set up a JustGiving Page
- Everyone who liked and shared our social media posts during the week, especially our World Down Syndrome Day ‘I can’ video, beautifully put together by Karl Svenson of Tadah Media and featuring lots of children and young people from our charity.

If you’ve got any ideas for Awareness Week 2024 then do let us know! Email [louise@downrightspecial.co.uk](mailto:louise@downrightspecial.co.uk)

## Downright Special Social Events

---

This half-term we've been focused on our Awareness Week events. We also had another Coffee and Chat Session for parents which everyone enjoyed.

The use of social stories, quiet areas and sensory toys has continued to get good feedback so we will continue to put these adjustments in place. In advance of any event please do give us a call if you'd like to chat about any other adjustments that might be helpful for your child or young person.

### Events Round-Up

**Saturday 1<sup>st</sup> April – East Riding Bikers Easter Egg Run – bookings now closed**

**Sunday 2<sup>nd</sup> April – Easter Egg Hunt – bookings now closed**

**Sunday 7<sup>th</sup> May – Circus Starr, West Park, Hull 4pm.**

- We have been allocated 50 tickets.
- Please email [louise@downrightspecial.co.uk](mailto:louise@downrightspecial.co.uk) to register your interest stating how many tickets you would like.

**Saturday 20<sup>th</sup> May – Bowling Party for Ages 4-12**

- 10.30am, Hollywood Bowl, Hull
- One game of bowling followed by food.
- Please book here: <https://www.ticketsource.co.uk/downrightspecial/t-ojmxrza>
- Bookings close on 15<sup>th</sup> May. Sorry no siblings on this occasion.

**Sunday 21<sup>st</sup> May – Youth Club Bowling Party for Ages 11-25**

- 3pm, Hollywood Bowl, Hull
- One game of bowling followed by food.
- Bring a friend if you want!
- Please book here: <https://www.ticketsource.co.uk/downrightspecial/t-moempjy>
- Bookings close on 15<sup>th</sup> May.

**Thursday 25<sup>th</sup> May – Parents/Carers Coffee and Chat**

- 9.30-11.30 Bodmin Road Church – No need to book just turn up!

**\*\*\*\*\*SAVE THE DATES\*\*\*\*\***

**Sunday 9<sup>th</sup> July – Downright Special Sponsored Walk, followed by a picnic in the park.**

Details to follow but it would be great if you could put this in your diary. We'd love to see lots of our families taking part and join us in East Park Hull!

**Sunday 10<sup>th</sup> December – Christmas Party**

12pm-3pm, Lazaat's, Cottingham. Bookings open in October.

## Downright Special Training

---

Our Summer term training programme is now available to book with a range of courses to help your child's education. Although many of these courses are aimed at school staff, parents are very welcome to attend these too.

This term we also have two sessions aimed specifically at parents: Toilet Training and Will & Trusts.

All courses and information sessions can be booked here: [www.ticketsource.co.uk/downrightspecial](http://www.ticketsource.co.uk/downrightspecial)

<b>Downright Special Education Training</b>	
Wed 26 Apr 2023, 3:45PM - 5:15PM	Co-ordination Difficulties for children with Down syndrome - Teams online course
Wed 10 May 2023, 3:45PM - 5:15PM	What is Sensory Integration? - Teams online course
Wed 24 May 2023, 3:45PM - 5:45PM	Working Memory for children with Down syndrome – Teams online course
Wed 14 Jun 2023, 3:45PM - 4:45PM	Preparing for Successful Transition – Teams online course
Wed 28 Jun 2023, 3:45PM - 5:45PM	Introduction to working with children with Down syndrome - Teams online course
Wed 12 Jul 2023, 3:45PM - 5:45PM	Introduction to working with children with Down syndrome - Teams online course

<b>'Parent Power' Training and Information Sessions</b>	
Wed 10 May 2023, 7pm-8.30pm	Planning for the Future: Wills & Trusts - Teams online information session, led by Paul Mounce of Gosschalks Solicitors
Thu 15 Jun 2023, 9:30AM - 12:30PM	Toilet Training for Children with Down Syndrome (all ages), Bodmin Road Church, Hull

## Building a Brighter Future – Preparing for Adulthood

---

For those of you with children age 13+, Hull City Council are running a Preparing For Adulthood Event on Wednesday 19<sup>th</sup> April 2023 1pm to 6.30pm at the Guildhall. This aimed at those of you who are starting to think about transition and post-16 options (usually from year 9 and above)

See the link below for more information:

<https://hull.mylocaloffer.org/becoming-an-adult/transition-documents/introduction-to-transition/>

This link also takes you to an area on the local offer with lots of helpful information about this key stage in your child's education.

## Downright Special Fridays

---

A reminder that any parents are welcome to pop in to see us on a Friday morning, even if your child has never attended or has outgrown our sessions or only comes to the afternoon groups. You can come just for a cuppa or to ask our staff for some help and advice.

If your child doesn't currently attend and you would like a place, then please do get in touch and we will see what we can do. We have already started the enormous task of planning the groups for September so please let us know if anything has changed for you!

Dates for next term

April 21<sup>st</sup>, 28<sup>th</sup>

May 5<sup>th</sup>, 12<sup>th</sup>, 19<sup>th</sup>, 26<sup>th</sup>

June 2<sup>nd</sup> – no group (half term)

June 9<sup>th</sup>, 16<sup>th</sup>, 23<sup>rd</sup>, 30<sup>th</sup>

July 7<sup>th</sup>, 14<sup>th</sup>

If your child attends fortnightly or attends an afternoon session, you will receive a separate email confirming dates.

***Our team put so much time and effort into preparing resources, so please email us on [office@downrightspecial.co.uk](mailto:office@downrightspecial.co.uk) as soon as you can, or contact your group leader if you are unable to attend a session.***

## Health

---

**Down Syndrome Care Pathway** <https://www.hullccg.nhs.uk/downsyndromehull/>

A revised edition of the Hull & East Riding Care Down Syndrome Care Pathway was published on World Down Syndrome Day and is now available to download.

Our Health Lead Sam has been working with local NHS organisations to review and update the pathway over the last few months. The main changes in this review (pathway version 5) include:

- audiology
- physiotherapy
- occupational therapy
- specialist gynaecology

The guidelines for the Annual Paediatric Checklists have also been updated to carefully reflect current best practice guidelines. This would not be possible without the significant input and expertise of Consultant Community Paediatrician (Neurodisability) Lorna Highet and her team.

In 2024 we aim to review the ante-natal and post-natal parts of the pathway. We also want to make connections within Local Authorities to ensure access and entitlement to Social Care provision for people with Down Syndrome locally is clarified and communicated.

If you are someone that can help Downright Special in meeting this aim or wish to be part of next year's pathway development, please contact [sam@downrightspecial.co.uk](mailto:sam@downrightspecial.co.uk)

## Maternity

We continue to try to make sure new and expectant parents get the best experience they can when they first hear the news that their baby has Down syndrome and we know that there has been a mixed experience for some of our most recent families. In March, Susanne (new parent contact) and Gillian (Charity manager) delivered training to the maternity ward staff at Hull Women and Children's Hospital about the charity, about Down syndrome and about how best to support new families. They will be repeating the training session in April and May to make sure we cover all the different shift teams.

## **Vision & Eye Care**

Issues with vision are very common in people with Down syndrome with almost all having difficulties with visual acuity, many needing to wear glasses with cataracts and nystagmus being more common in children with Down syndrome than the general population. We also know that Keratoconus (when the cornea starts to become conical, thin and fragile) is more common in people with Down syndrome, and although rare in children can start to develop in adolescence. It can seriously affect vision if not treated early. This is why it is very important that children and adults with Down syndrome have regular eye checks at the eye clinic, or with their local optician when they get older.

There are lots of resources available to help you understand more about vision and Down syndrome, many of which are based on research from Maggie Woodhouse of Cardiff University. Here's a few links we'd recommend:

- DS UK has some really good short videos by Maggie covering wearing glasses, eye care, use of eye drops, nystagmus etc. <https://downsyndromeuk.co.uk/health/eye-care/>
- The DSA also has lots of good publications: <https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/eyes/>
- The DSA is running a free webinar on 25<sup>th</sup> April 2023, 2-3pm, delivered by Maggie Woodhouse: Book here: [DSA|getsightrightwebinar](https://www.downs-syndrome.org.uk/about-downs-syndrome/health-and-wellbeing/webinars/)
- Getting glasses to fit correctly can also be a challenge. Check out these websites for glasses that are designed specifically for children with Down syndrome:
  - <https://erinsworldframes.com/>
  - <https://www.tomatoglassesuk.com/>
- Appendix 2 (page 17) of the Hull Down Syndrome Care Pathway has information on guidelines for referral to the Ophthalmology service at Hull's Eye Hospital. <https://www.hullccg.nhs.uk/downssyndromehull/>

In addition, Sam and student John have been working on a 'postcard' style leaflet that you can take to your optician to remind them to check for some of the common eye conditions and with a link to the DSMIG information for healthcare professionals on vision problems in Down syndrome. We hope to be able to share that with you very soon.

## Staff News

---

Our Deputy Charity Manager, Kate Long, has decided to leave her role with the charity. Kate has decided to take a break from working to spend more time with her family. Huge thanks to Kate for her contribution to the work of the charity over the last year as Deputy Charity Manager and we wish her all the very best for the future.

Of course, Kate and her family will continue to be active members of Downright Special and we are sure you will see them very soon at a social event or Friday group session.

We also say farewell to student John Lawler who has been on placement with us as part of his degree in Learning Disability Nursing. John made a significant contribution to updating the Care Pathway, helped with responses to health queries from individual families and supported our teaching staff on outreach visits and at our Friday groups. We wish you lots of luck with your future studies John!

## Lending Library

---

We have a huge range of books and resources that you can borrow from us.

Our entire catalogue can be viewed online. You can browse for books and resources and then request/reserve the ones you'd like to borrow. Books can be borrowed for up to four weeks.

Email [louise@downrightspecial.co.uk](mailto:louise@downrightspecial.co.uk) to request library login details or to request a pdf version of the catalogue.

## CEA Card

---

Have you heard of the CEA Card?

The CEA Card is a national card scheme developed for UK cinemas by the UK Cinema Association (UKCA). The Card enables a disabled cinema guest to receive a complimentary ticket for someone to go with them when they visit a participating cinema. To apply, the person requiring assistance must be 5 years of age or older and be in receipt of certain benefits such as DLA or PIP. It costs £6 to apply but given the cost of cinema tickets you very quickly get your money back!

For more information check out their website: <https://www.ceacard.co.uk/>

## Easy ways to support Downright Special

---

**Easy Fundraising** is an online shopping directory which features major online stores, including eBay and Amazon. Visit [www.easyfundraising.org.uk](http://www.easyfundraising.org.uk) whenever you shop online and we'll receive a free donation of up to 15% from every purchase you make and it won't cost you a thing! We've had a few new people sign up to this recently and we are so grateful for the support!

You could purchase items from our [Amazon Wishlist](#). This list is regularly updated with items we need such as stationary, specialist books, items for events such as our Easter Egg Hunt or Awareness Week Café. [https://www.amazon.co.uk/hz/wishlist/ls/1PGPTF1B551EW?ref\\_=wl\\_share](https://www.amazon.co.uk/hz/wishlist/ls/1PGPTF1B551EW?ref_=wl_share)

## Suggestions and Ideas

---

If you wish to chat about anything in this update, have suggestions or ideas for events, training or support you would like, or you'd like to pass on any tips, please do get in touch.

We wish you a very Happy Easter and we look forward to seeing you after the break!