



Downright Special Update – December 2022

Welcome to our last update of 2022! 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.

Downright Special Training

Our Spring term training programme is now available to book with a huge range of courses to help your child's education. Although most of these courses are aimed at school staff, parents are very welcome to attend too. We'd particularly recommend the Supporting Positive Behaviour course as suitable for parents. Courses can be booked here: www.ticketsource.co.uk/downrightspecial

Wed 11 Jan 2023, 3:45PM - 5:45PM	Introduction to working with children with Down syndrome - Teams online course
Wed 25 Jan 2023, 3:45PM - 5:45PM	Introduction to working with children with Down syndrome - Teams online course
Wed 8 Feb 2023, 3:45PM - 5:00PM	Teaching Vocabulary for pupils with Down syndrome - Teams online course
Wed 22 Feb 2023, 9:30AM - 2:30PM	Supporting Positive Behaviour - Teams online course
Wed 1 Mar 2023, 3:45PM - 4:45PM	Colourful Semantics for pupils with Down syndrome - Teams online course
Wed 15 Mar 2023, 3:45PM - 5:00PM	Curriculum Access and Differentiation for pupils with Down syndrome - Teams online course
Wed 29 Mar 2023, 3:45PM - 5:45PM	Promoting Social, Emotional and Mental Health and Wellbeing in pupils with Down Syndrome - Online

Downright Special Social Events

Since the last update we've had a busy social calendar with our Halloween dance parties, Youth Club Bowling event and our Christmas party. We've had some positive feedback on the changes we've made to make these events more inclusive such as social stories, quiet areas and availability of the sensory tent / sensory toys but please do let us know if you have any other suggestions.

We are also delighted to have a new volunteer helping at events – Toni Bullock 😊

We are now making plans for the 2023 with our first event open for booking.

Events for children/ young people

Sat 21st Jan 2023, 12pm-2pm, Soft Play Party at Monkey Bizness, Hull for our Under 12s.

Book here: <https://www.ticketsource.co.uk/downrightspecial/t-nojaqae>

Events for parents

Thurs 23rd Feb 9.30am: Parent Power Coffee Morning at Bodmin Road Church.

- A chance for parents to get together over a cuppa while the children are at nursery, school or college
- Little ones not at school are welcome to come along too.
- No need to book but if you can let us know if you are coming it helps us to plan.

Complex Needs Steering Group Update

To sum up the ongoing work that the complex needs group is doing, the best way is to share the pledge that the group has developed

“Downright Special recognizes that each individual with Down's syndrome is unique and that some may have more complex needs. We pledge to create an environment where all individuals and their families feel welcome and supported, regardless of diagnosis or ability.”

The group continues to talk about the experiences of parenting a child with more complex needs and to consider how the charity can respond to those experiences. Ideas so far have focussed on social events, for example the group are co-developing a checklist to be used when assessing venues and have volunteered to be parent consultants when reviewing social venues. Another theme has been around feeling understood by and connected to other families. Moving forwards, we will be developing a training session for all parents/carers which will raise awareness about dual diagnosis of Down Syndrome and autism. The group has also identified sources of online and real-life support both national and local that they find relatable and will be sharing these with everyone.

Next session will be 19th January (evening) with the sessions culminating in a plan for some short-, medium- and longer-term projects.

This is a long-term project so please do get involved if you would like to contribute to shaping our strategy around Complex Needs. **Email Sam for more details and to join:** sam@downrightspecial.co.uk

Building a Brighter Future – Preparing for Adulthood

This group is facilitated by Gillian Bowlas, Charity Manager, and has been meeting monthly, with 8 parents involved who have children of secondary age and above. They have been looking at the four areas of preparing for adulthood – education and employment, good health, independent living and friends, relationships community. As well as identifying the issues faced and looking at what could be done to help resolve some of these issues, the group has enjoyed sharing experiences, knowledge,

and resources. The next session is **Tuesday 24th January 7pm (online via Teams)**. This is an ongoing project and if anyone else wants to get involved at any time then just let Gillian know. gillian@downrightspecial.co.uk

Downright Special Fridays

We have a few spaces available across our groups at the moment. If your child doesn't currently attend or hasn't been for a while, then do get in touch and we'll see what we can do! We've had this lovely feedback recently from one of our parents so please do come along if you can:

"he's doing so well and I really think it is because he has been coming to Downright Special since he was a baby."

Our Friday morning group will run on the following dates:

Jan 6th, 13th, 20th, 27th

Feb 3rd, 10th

Half term

Feb 24th

March 3rd, 10th, 17th, 24th, 31st

If your child attends a Friday afternoon session, you will receive a separate email confirming new dates.

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

Health

With all the stories about Strep A and Scarlet Fever in the news, Sam our Health Lead has sent out an email to everyone with some information from trusted sources, so check your inbox to find out more.

There is nothing around to suggest that children with Down Syndrome are more susceptible to Strep A or scarlet fever than any other children, however as we are all aware, children with Down Syndrome can present differently *with any infections*, deteriorate more quickly and/or remain poorly for longer. For this reason, it is important to remember all those infection prevention steps we took so seriously during COVID. So lots of handwashing, using tissues, keeping well fed and hydrated, staying away from busy places or vulnerable people if poorly. The DSA have a webpage about infection and infection prevention that is a good reminder [Infections and Immunisations - Downs Syndrome Association \(downs-syndrome.org.uk\)](https://www.downs-syndrome.org.uk/infections-and-immunisations-downs-syndrome-association/)

You can also download https://www.downs-syndrome.org.uk/wp-content/uploads/2020/05/DS-infographic_TopTipsTriagingTreating.pdf which is a sheet aimed at clinicians. If you have a Downright Special passport this is included but if not, then printing or screenshotting this sheet and having it with you could be helpful if the worst happens and you end up at GP or A&E feeling that

your concerns are not being addressed. Be confident that you know your child best and know when they are not “their normal”.

Awareness Week 2023

Down Syndrome Awareness Week runs from 20th to 26th March 2023. We are beginning our planning for this special week in the calendar but please do let us know if you have any ideas for awareness raising or fundraising or if you would like to get involved. Email louise@downrightspecial.co.uk

Easy ways to support Downright Special

The Movement for Good awards are donating £1000 to Charities.

To nominate Downright Special please click [here](#) to complete the short nomination form below: Our Charity Number is: **1175863** Charity Type: **Disability**

Winners are drawn end of December.

Easy Fundraising

Easy Fundraising is an online shopping directory which features major online stores, including ebay and Amazon. Visit www.easyfundraising.org.uk whenever you shop online and we'll receive a free donation of up to 15% from every purchase you make.

Asda Foundation Green Token Giving

Vote for Downright Special online as part of the **Asda Foundation Green Token Giving**. The local cause with the most online votes will receive a **£500 donation** with second place receiving £400 and third place £300.

Vote now until midnight on Saturday 31st December 2022.

Its quick and easy, visit this link www.asda.com/green-tokens and select Kingswood from the drop-down box.

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 would like to wish all our Downright Special Families a very Merry Christmas and a Happy New Year. See you in 2023!