



Downright Special Termly Update

End of Term Update July 2021

Welcome to our end of term update. The aim of these updates 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, health and education news, and any particularly good hints, tips, and contacts that we come across.

Thank you to all of you for your support and understanding this year as we have navigated the challenges of the pandemic and tried our best to continue to support you all in this most difficult year for all of us.

We do officially break up for the summer on Friday 23rd July but if you do need us over the summer then don't hesitate to get in touch on office@downrightspecial.co.uk or call 01482 420160. Leave a message and someone will get back to you.

Friday Group

Our Friday groups begin to return from Friday 17th September. You (and your child's school if appropriate) should all have received an email with details of the return and dates for your child for this term. If you think you haven't had an email then do let us know.

Our staff will be back at work w/c 6th September, preparing for the groups and making sure our risk assessments are updated to reflect whatever the Covid situation and government guidance is at that time. We will continue to do whatever we think is necessary to keep you and your children as safe as possible.

Term Dates

Friday Term dates for next half-term are:

Sept 17th, 24th

October 1st, 8th, 22nd

For those of you whose lessons are fortnightly or monthly, the email from your Downright Special teacher will detail your lesson dates & times.

Children supported in schools/nurseries

Our teachers Laura, Katie and Nicola continued to support children in nurseries, pre-schools, primary and secondary schools throughout the last year and will continue to do so next year. Their work includes:

- visiting schools and observing children
- giving advice on differentiating the curriculum
- sending resources
- attending annual reviews (usually on-line)
- writing reports for EHC Plans.
- providing training to school staff

You can contact them at anytime if you have any questions about your child in school.

Health

Health and Education Directory 0-18 months

Our Downright Special Health Lead, Sam Findlay has been working hard to develop a document to translate the Down Syndrome Care Pathway into a “Health and Education Directory” for each age group of children to make it easier for parents to find the information they need relevant to the age of their child. The first directory for children aged 0-18 months is almost ready to be shared with parents and work will begin on the

next age range in the autumn, with a plan create documents for each age up to age 16+, so watch this space!

Hospital Passport

Sam has also been working on developing a 'hospital passport' that you can use to detail the information that you might need to share with hospital staff should your child need to be admitted. The passport would include information about your child or young person's physical health, medication, how they like to communicate, how you will know if they are in pain or unwell etc. Also included are useful Makaton signs for being in hospital, information on infection in children with Down syndrome and widget symbols as a visual aid. Sam is looking forward to sharing this with you very soon!

Dual Diagnosis (DS & Autism)

We have been very aware that we need to do more to support families whose child has additional needs as well as Down syndrome, such as Autism. We have put in place 1:1 social communication sessions for some of our Friday children who benefit from a different approach and this has been successful for those children. However we would like to be able to do more, so Sam will be leading some work to try to understand from parents what they would find helpful for us to provide. We want to hear from you so that we are providing what you need and want.

Care Pathway

The work with Hull CCG and other NHS groups to keep developing and updating the care pathway has stalled as the NHS focused on Covid but we are pushing to get the working party up and running in September and have an initial meeting planned with the CCG in September.

Training Courses

We have a full programme of education – related training courses planned for the Autumn term including:

- Introduction to working with children with Down Syndrome
- Supporting Positive Behaviour

- Teaching Vocabulary
- Curriculum Access and Differentiation
- Colourful Semantics
- Working with Numicon

Most of these continue to be delivered online with the exception of Behaviour and Numicon training as these are both longer courses that benefit from being face-to-face as they work better with lots of practical activities.

All courses are open to school and nursery staff and parents.

Bookings can be made on: <https://www.ticketsource.co.uk/downrightspecial>

Training for Parents

This year we ran two sessions specifically for parents:

- Sensory Processing
- Toilet Training

Next year we would like to run a regular programme of training specifically for parents so if you have any suggestions for what you would like to see then let us know.

Already planned are:

- Signing for parents
- Toilet Training

And we have had suggestions around financial planning, wills & trusts, mental capacity act but please let us know if you have anything else you would like us to put on.

Email training@downrightspecial.co.uk with your suggestions.

Social Events

Our last social event of this term is Sunday 25th July with our two dance parties for our pre-school children and primary age children. We have decided not change any of our Covid guidelines for this event given the high rates in our area and our desire to keep everyone safe. This means:

- One adult or carer to accompany the child
- No siblings
- Accompanying adult to wear a face covering
- Scan in to test and trace and sanitise your hands on arrival.

We are looking forward to returning to have a full programme of social events from September. Keep an eye on your emails for any news!

Maternity Services

We were really pleased to have worked with Positive About Down Syndrome to deliver online training to maternity units in Hull, Grimsby, Goole, Scunthorpe, York and Scarborough this term. Hopefully we will be delivering another couple of training sessions this year. We have been in close contact with lead midwife for the new Humber Coast and Vale Local Maternity System and will be working with her to improve services across the region.

In addition we have also been invited to take part in a national initiative led by NHS England and NHS Improvement looking at the need to get better systems and processes firmly embedded to ensure pregnant women and their families are better informed of their rights, choices and support available to them.

Building a Brighter Future

At the other end of the age spectrum from maternity services, next year a priority is for us to restart our 'Building a Brighter Future' project looking at what support we need to provide to help our young people over 16 as they transition to adult services. Many of our young people who joined Downright Special when it first started have reached this age and we would like to be able to keep supporting them through this time.

Fundraising

Behind the scenes we continue to spend a lot of time applying for grants to keep us funded for the next 12 months. This has been especially important this year as lots of community fundraising events couldn't happen.

However, we want to give a huge thank to everyone who supported us this year despite the difficulties. You have all been amazingly generous and we are still blown away by the amount that was raised during this year's awareness week – over £12,000!

Louise and our volunteer Lisa Bloomer are already getting their thinking caps on around what we can be doing next year so let us know if you have any ideas or would like to get involved. In the meantime, there are lots of other ways you can help without it costing you penny – just a couple of extra clicks when you are shopping online!

Ways you can help

- Shop online via <https://www.easyfundraising.org.uk/causes/downrightspecial/> Most of the high street shops and other organisations are on there and donate a % of the purchase price to charity.
- Go via Amazon Smile for your Amazon shopping. <https://smile.amazon.co.uk/>. On each site a percentage of the purchase price comes direct to our charity.
- Send e-cards using Don't Send Me a Card. You can send birthday cards, thank you cards or special occasion cards and support a charity of your choice. <https://www.dontsendmeacard.com/>
- Purchase items from our Amazon wish list: <https://tinyurl.com/28sdxevx>

Benefits

Just a reminder that Louise Smith is our resident DLA guru so if you need some help with applying for Disability Living Allowance or want to appeal against a decision then she can help you.

Over the summer Louise is attending training on Personal Independence Payment (PIP) which replaces DLA for those over 16. She is looking forward to being able to support parents with applying for this benefit too.

Contact Louise on louise@downrightspecial.co.uk or call 01482 420160.

Social Media

Our new Instagram account is now up and running! Thank you to everyone that has followed us so far and thank you to volunteer Lisa Bloomer, mum to Charlie, who is managing the Instagram account for us.

You can follow Downright Special here: https://www.instagram.com/downright_special/

If you'd like to share any pictures of your child or young person, perhaps celebrating a milestone or perhaps just having fun doing their favourite activity then we'd love to see them! Please email pictures you'd like to share to: lisa.bloomer@downrightspecial.co.uk

We may also share pictures on our other social media pages:

Public Facebook: [@DownrightSpecialNetwork](#)

Twitter: [@downright21](#)

LinkedIn: <https://www.linkedin.com/company/downright-special>

Don't forget we also have a closed, private Facebook group for our parents and carers as a way to stay in touch, share tips and ask questions.

You can join this group here:

<https://www.facebook.com/groups/DownRightSpecialNetwork>

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.

In the meantime, please stay safe, take care and don't forget we are here to help you in any way we possibly can.

Have a lovely summer everyone!

Best wishes

The Team at Downright Special