

Downright Special Termly Update

Edition 2 – May 2020

Welcome to our second Termly 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. This second edition is (of course) focused on what is going on in the charity during the current COVID-19 crisis.

Staffing during the COVID-19 crisis

Our teaching staff (Laura, Katie and Nicola) continue to work from home providing support, resources, advice and information to families, schools and nurseries. A donation from Warburtons meant we could buy printers for them to use at home so they could continue to make and post out resources.

Sam, Jill and Lauren are supporting their Friday families by phone, text and WhatsApp and arranging for resources to be sent out where needed.

Heather is also volunteering behind the scenes helping to prepare resources.

We took the difficult decision to furlough Sarah (Charity Coordinator) and Louise (Community Fundraiser) from 20th April. We will let you know as soon as they are back at work. In the meantime their roles are being covered by Gillian (Charity Manager).

Friday Group

We have been working hard to transform our usual Friday sessions into an on-line version of our teaching groups.

- Laura, Katie and Nicola have begun to deliver lessons via Zoom for the children who usually attend our Friday sessions. The first trials have worked well and so we will

gradually roll these lessons out to more of the groups. For those children who cannot attend a zoom lesson or find it difficult to cope with working this way, then we are more than happy for them to just get the resources sent home to work on.

- Sam (with help from Erin and Anya) is running a weekly Facebook Live version of Magic Bag on our closed group for parents. Find them every Friday at 11.30am at <https://www.facebook.com/groups/DownRightSpecialNetwork/>

Children supported in schools/nurseries

For those children who don't attend a Friday session and we only support in school or nursery, then please don't hesitate to get in touch with Laura, Katie or Nicola if you would like some help, advice or resources sent home. We are also more than happy for schools and nurseries to contact us if they would like any help at all with differentiating the work they are setting for their classes during this time.

Term Dates

There will be no zoom sessions or Magic Bag on Friday 8th May as this is a bank holiday. Our staff worked through the Easter break to ensure we could be ready to start Zoom lessons after the holiday and so they are ready to have a day off!

Last day of this term is Friday 22nd May, so no zoom lessons or Magic Bag on Friday 29th May which is half-term.

Social Events and Fundraising

Our social and fundraising events are cancelled for the next few months until further notice. We will look to reschedule events once the government advice means that it is safe and appropriate to do so.

We have tentatively rearranged our World Down Syndrome Day pop up café to Saturday 21st November so please pencil this into your diary.

Our Christmas party date is also now changed to Sunday 6th December (it was advertised as Saturday 12th Dec) due to availability of the venue.

Our income for the year has been affected significantly by the cancellation of fundraising events and we are working through what this might mean for the charity and the services we will be able to deliver next year.

Easy ways you can help without it costing you anything would be to:

- 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, special occasion cards and support a charity of your choice.
<https://www.dontsendmeacard.com/>

Training Courses

Our training courses are all cancelled until further notice but we will look to provide on-line training should the need arise and we are available for 1:1 advice over the phone.

Makaton are offering their Level 1 and Level 2 courses online at the moment at about 50% of the cost of face to face training. <https://www.makaton.org/training/OnlineWorkshops>

Makaton also have lots of special offers on their books of signs including core vocabulary, food and drink and national curriculum. <https://www.makaton.org/shop/specialOffers>

Toilet Training

Some of you may see the lockdown as an opportunity to start toilet training with your child. If you'd like any advice then you can contact Laura or Gillian who would normally run the toilet training course for Downright Special families. Here are some other places for help and advice:

- Bladder and Bowel UK have loads of really good resources, including a 'Top Tips for getting ready for toilet training children with Down syndrome and other learning disabilities'
<https://www.bbuk.org.uk/children-young-people/children-resources/>
- ERIC have a helpful guide to toilet training children with additional needs:
<https://www.eric.org.uk/Handlers/Download.ashx?!DMF=9b1c4466-ef97-436f-ad8a-9d53ffddb6a9>

- DSUK Going POTTY?! Toilet training advice & tips 4 children w Down syndrome (under 5s) <https://www.facebook.com/groups/219984462212935/>
- DSUK Toileting issues 4 children & young people w Down syndrome aged 5+ <https://www.facebook.com/groups/2696424470414491/>
- DSUK Pants 4 School leaflet https://downsyndromeuk.co.uk/pants4school.pdf?fbclid=IwAR0K4hjnqmVZf4kBU6Aa0R94dLCZBNgvMZ_1XD05_zeF_B2KYMEhaX8K_kA

EHCP News

Hopefully you should have received our 'Top Tips for Education Health and Care Plans' by email a few weeks ago. You can also find a copy on our website:

<https://www.downrightspecial.co.uk/resources>

The government announced on 30th April that they had made temporary amendments to the SEND regulations to temporarily relax the legal duty on local authorities and CCGs.

<https://www.gov.uk/government/publications/modification-notice-ehc-plans-legislation-changes>

For a summary of the changes in force from 1st May to 25th September, Special Needs Jungle have this short article: <https://www.specialneedsjungle.com/coronavirus-ehcp-laws-temporarily-relaxed-as-las-told-to-just-do-their-best/>

For information on the impact of COVID-19 on EHCPs, annual reviews etc. in our area, the local offer websites have guidance on what you can expect.

For East Riding, you will find info here

<http://eastridinglocaloffer.org.uk/coronavirus/>. Have a look under FAQs. There is also lots of info on what services are still running and how you can contact the SEND team.

For Hull there is loads of COVID-19 info on the local offer website here:

http://hull.mylocaloffer.org/s4s/WhereILive/Council?pageId=5127&fbclid=IwAR2ITj_HlBQP00_AGnWhNZ8fAcUurP_wjKVprCy5LbLzmclQzo-Clu8tQDVo

Health

- For the most up to date advice on COVID-19 and Down Syndrome then the Down Syndrome Medical Interest Group is a good place to start:
<https://www.dsmig.org.uk/covid-19-and-down-syndrome/>
- The Royal College of Paediatrics and Child Health has published a useful on deciding what level of medical help your child might need if unwell
https://www.rcpch.ac.uk/sites/default/files/2020-04/covid19_advice_for_parents_when_child_unwell_or_injured_poster.pdf?fbclid=IwAR2plqXnnJxy6RomiVx0R9a0xHBEgeFv9IQkpbpuiCpi9eKCZENHingSiTI
- Download the Top Tips for triaging kids with Down Syndrome poster
<https://www.downs-syndrome.org.uk/download-package/top-tips-for-triaging-treating-children-with-downs-syndrome/?fbclid=IwAR0y-S-ey4m59NczFsgBEtsHtsvwDq-3v-KGkS4ihLFEZefXW1j3Qh1qvnw>
- UK Covid-19 and Down's syndrome survey
<https://www.surveymonkey.co.uk/r/28TDZCN>

The Down Syndrome Research Foundation and Positive About Down Syndrome are trying to reach as many UK based families to collect data to establish some baseline findings on: How many people with DS in the UK have had a confirmed case of Covid19 and how many suspected; how has it affected those people, what treatment did they require and how did they respond; is it possible many are not showing symptoms, much like neuro-typical children/adults. They would like all people with DS in the UK represented, Covid19 symptoms or not. **Please complete the survey by 5th May.**

Benefits

Some of you may have had changes to you financial situation as a result of the current crisis. Here are some useful websites with benefits and money advice for parents of children with disabilities.

- <https://contact.org.uk/advice-and-support/benefits-financial-help/>
- <https://www.downs-syndrome.org.uk/for-families-and-carers/benefits-and-financial-help/>
- <https://www.mencap.org.uk/advice-and-support/benefits-people-learning-disability>

- <https://www.citizensadvice.org.uk/benefits/coronavirus-check-what-benefits-you-can-get/>

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.