



# York Down Syndrome Support Group Volunteers Handbook

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## Welcome!

Thank you for choosing to volunteer for York Down Syndrome Support Group, helping us to create and develop the conditions which will enable our children with Down syndrome to attain their full potential. As a parent-led organisation, volunteers are a vital part of making sure that we offer the best service we can to the children and families in York and surrounding areas.

It is very important to us that our volunteers feel valued, understood and proud to be part of York Down Syndrome Support Group and this handbook is here to explain the things you need to know about volunteering with us. I hope you will find it helpful. If you have any questions about what's covered or need more information then please don't hesitate to talk to me or anyone else in the team.

Thanks again for volunteering to help make a difference to the lives of children with Down Syndrome in our local area.

Charley Murray

Chair

## About York Down Syndrome Support Group

### Who we are

We are a parent led support group based in York in the UK. Established in 2012, our overall aim is to create and develop the conditions which will enable our children with Down syndrome to attain their full potential. We aim to support all those involved in the lives of our children including family members and professionals.

### What we aim to do:

To assist families and professionals in York and the surrounding area in the care of children with Down syndrome.

- offer personal support to new parents or parents with an antenatal diagnosis in whatever form they prefer
- host sessions where families can come together to chat and play
- have regular social events for the whole family
- lend useful resources to families and professionals
- provide training for parents and professionals
- provide speech and language and/or child development groups
- promote the awareness of Down syndrome and encourage the inclusion of all within society
- support high quality research about any aspect of living with Down Syndrome

### Background

Our group started to get going formally in 2012 and our first 3-21 Saturday Club was in April of that year. We don't have any 'formal' paid for membership. We currently keep in contact with approximately 70 families via mailing lists (email and postal) and our families Facebook group.

### Committee

All our main group work is undertaken on a voluntary basis by the committee. The committee is made up of 9 people who meet monthly.

## Ways to Get Involved

Our volunteers help us in lots of different ways, depending on what their interests and skills are, how much time they have and what vacancies we have available. Here are a few examples of what sorts of things people do today or could do for us in the future:

- **Fundraising**
  - o Organise fundraising events
  - o Support other people's fundraising – sending leaflets and information, collecting donations etc.
  - o Here are some examples of the things people do for us: hold a cake bake, host a coffee morning, run a second-hand bookstall, have a collection tin at work or at a club, run a raffle at an event, do a sponsored walk, run or cycle.
- **Helping behind the scenes**
  - o Making resources, filing, laminating, posting, ordering
  - o Make teas/coffees and preparing snacks for the children
  - o Set up and clear up the toys
  - o Support one of our groups
- **Look after our website, email system and IT**
- **Book-keeping**
  - o Keep our accounts up to date and our accounting systems and practices in good order
- **Helping organise events/courses**
  - o Book venues and support compilation of risk assessments
  - o setting up IT, audio-visuals, serving refreshments, signing in of participants, preparing/distributing resources, collating feedback.
- **Support families**
  - o Benefits advice
  - o Advice on SEN law, code of practice and EHCPs
  - o Signposting to other services
- **Manage our communications**
  - o Design leaflets, invitations and publicity
  - o Write newsletters, manage social media, press releases and information on our website
- **Become a trustee**
  - o Get involved in making sure the charity is run properly and help shape the future of the organisation

## **Mutual Expectations**

It's really important to us that you enjoy being part of York Down Syndrome Support Group and that you feel that you get the best you can out of your role as a volunteer. As part of this it is helpful to be clear about our commitment to you and equally the commitment we would like in return.

## **What You Can Expect From Us**

You can expect that we will:

- Always value, appreciate and respect what you do, whoever you are and whatever your background
- Act in a considerate way
- Make sure your role is clear, that you understand the time commitment involved and how long it will last
- Help you with any training and support that may be required to fulfil your role
- Make sure you have any resources or equipment needed to carry out your duties
- Support you with regular meetings or discussions to check how things are going
- Keep you up to date with what's going on in the charity and how you are making a difference
- Give you open, honest and fair feedback on how you are getting on in your role
- Listen openly to anything you say and make sure you have the opportunity to change your mind about volunteering with us without any pressure

## **What We Expect From You**

At York Down Syndrome Support Group we aim for high standards in everything that we do, and we expect all of our volunteers to do the same.

To make sure you get the most out of volunteering for us we ask that you:

- always treat all associated with York Down Syndrome Support Group including supporters, other volunteers and families who use our services with respect, consideration and appreciation
- recognise that our primary concern is the needs of the children and families that we support
- act in a professional way whenever you represent York Down Syndrome Support Group in public
- act in a way that doesn't discriminate against or exclude anyone
- let us know, with as much notice as possible, if you are not able to fulfil your voluntary commitment or wish to give up your role entirely. This allows us to make alternative arrangements if necessary
- talk to us if you are ever unclear about any aspect of your role

## **Important Stuff You Need to Know!**

As a volunteer it's important that you are aware of, and familiar with, York Down Syndrome Support Group's policies and procedures. Please take the time to have a read of them and ask questions if anything is unclear.

### **Expenses**

We want the opportunity to volunteer to be open to all and no one should feel unnecessarily out of pocket because of volunteering for us. It remains the decision of the volunteer as to whether they want to claim expenses or not but York Down Syndrome Support Group will reimburse volunteers for any reasonable expenses, including travel to/from an event or our premises. Please try to submit expenses in a timely manner using our expenses form. We will need copies of receipts and tickets to process any claim and claims will only be accepted up to a pre-agreed amount. A copy of our expenses form can be requested by email at [contact@ydssg.org](mailto:contact@ydssg.org). Alternatively download from our website

### **Boundaries**

Many of our volunteers have contact with the people we support and the professionals we work with in a personal capacity as friends, family, or colleagues. Having clear boundaries is very important in making sure that everyone we support has the same level of service from us and ensuring that access to these services is done in an open and transparent way. Please take care to avoid any conflicts of interest.

YDSSG Volunteers who also have roles supporting individuals or families in the group should make sure they are clear about the boundaries between their roles and the basis upon which they undertake work be it volunteering or in a paid capacity.

### **Confidentiality**

Volunteers must maintain confidentiality during their time with York Down Syndrome Support Group. In the course of your role, you may come across or be entrusted with sensitive information about the people we support, other volunteers, staff, our donors and fundraisers. You may also have access to sensitive information about the work of the charity including confidential internal financial information and confidential information about children and families. This information must be kept private and must not be divulged or shared at any time either during or after your time with us, unless sharing this information is required by law.

### **Press and Media**

The press and media (including social media) is a very useful and important way of getting our message across, raising awareness of the work that we do and portraying Down Syndrome in a positive light. Equally, handling the media and press badly, can have a very damaging effect on the charity and on the public perceptions of York Down Syndrome Support Group.

For this reason, volunteers are not allowed to talk to the press, write letters or post on social media as representatives of York Down Syndrome Support Group without prior written permission from the Charity Chair or the board of Trustees. If you do want to highlight an issue or have an idea for something that would be good to share publicly then we always welcome the involvement of volunteers, but you must ask permission before you act as a spokesperson for the charity.

### **Charity Property**

As part of your volunteering role, you may be entrusted with various items such as office equipment, computer equipment, mobile phones, and general office resources. Please take care of these items as if they were your own and return them to us when they are no longer needed, or you leave your role.

Charity Property should only be used to support the volunteering duties you have and should not be used for personal use.

### **Safeguarding**

York Down Syndrome Support Group is involved in working with or supporting children, young people and vulnerable adults in a wide variety of ways and we take safeguarding very seriously. If your role involves working with these people you will be required to undergo a DBS check as part of our policy on safeguarding. It will also be important for you to become familiar with our Safeguarding Policy which can be found on our website. Our Designated Safeguarding Trustee is Laura Swales and any concerns should be raised with her in the first instance.

### **Health and safety**

York Down Syndrome Support Group is committed to maintaining and promoting the health, safety and wellbeing of everyone who works for us, volunteers for us, visits us or uses our services.

Any activities carried out on a voluntary basis are covered by the same health and safety legislative requirements as those carried out as if you were a York Down Syndrome Support Group employee. It's therefore important that you understand and accept your personal responsibility towards promoting and maintaining health and safety standards to provide a safe working environment for all.

All activities and events must have a risk assessment in place.

It's important that you:

- carry out your duties without endangering either your own health and safety, or that of colleagues, third parties and/ or the general public
- comply with all relevant instructions and procedures relating to safety and follow guidance provided by York Down Syndrome Support Group

- inform us of any personal health and safety requirements that you have.

If you are not sure about your role with regards to health and safety, or you are aware of any potential health and safety issues please let us know as soon as possible.

### **Accidents and incidents**

If you feel that it's a real emergency, please contact the emergency services immediately.

All accidents and incidents must be reported to the committee as soon as possible. We have an accident form to record any incidents. This form can be found on the policies page of the website <https://www.ydssg.org/policies>. All accident forms should be logged with the Chair of the committee and emailed to [contact@ydssg.org](mailto:contact@ydssg.org). Forms will then be logged within the YDSSG electronic google drive.

### **Data protection**

York Down Syndrome Support Group is committed to meeting its obligations under the Data Protection Act - a legal act that protects people's personal information. Depending on your role you may have access to and handle the personal information of our families or our staff and other volunteers. If this is the case, you must read and be familiar with our Data Protection policy.

### **Equal opportunities**

York Down Syndrome Support Group believe that discrimination is unacceptable. We won't discriminate against any volunteers because of their age, disability, ethnic origin, gender, marital status, nationality, political beliefs, race, religion, sexual orientation or socio-economic background. All applicants for volunteering roles will receive fair treatment and will be recruited purely based on their suitability for an available role. For further information please see our Equality and diversity policy

### **No smoking policy**

Smoking is not permitted on York Down Syndrome Support Group property or when staff and volunteers are involved with York Down Syndrome Support Group activities.

### **Insurance**

York Down Syndrome Support Group has both Public Liability Insurance and Employers Liability Insurance. Our registered volunteers are covered under both these policies in the unlikely event of any claim.

### **Car drivers**

If you are using your own car to carry out any of your duties as a volunteer you MUST tell your insurance company about this. This will ensure that your own insurance covers you in the event of an accident or incident whilst you are carrying out your volunteering duties. Your car is not covered by any insurance held by York Down

Syndrome Support Group. We also ask that you read and familiarise yourself with our 'Using your own Vehicle' Policy.

### **What we say**

You may notice that at York Down Syndrome Support Group we have a certain way that we talk about people with Down syndrome and our beliefs about inclusion in families, schools, clubs, and the communities in which our families live. We use 'person-first' language: for example, we would always say 'a person with Down syndrome' and **never** 'a Down's person' or a 'Down's'. We would also never say a person 'suffers' from Downs syndrome or that there is a 'risk' that someone would have a baby with the condition. We would ask that you also commit to using the right language that respects the people that we support and that you understand the high expectations we have of people with Down syndrome. Included in this pack (Appendix 1) is some further information on 'What to say and What not to say' and some common myths and facts about the condition that you may find helpful in understanding more about Down syndrome and our ethos as a charity.

### **What we wear**

As a volunteer for York Down Syndrome Support Group, you're also an ambassador for the organisation and presenting a positive image to the public, our supporters and our beneficiaries is important. We rely on you to use your judgement to dress appropriately for your role but expect your appearance to be tidy and smart.

## **How much you mean to us**

### **Acknowledging your contribution**

We really appreciate the work that our volunteers do, and we couldn't continue without you! We strive always to say thank you each and every time you do some volunteering for us. We may also, with your permission say thank you more publicly on our website and social media and we always acknowledge those who have provided vital volunteer hours when we publish our annual report.

We can also provide you a written reference if you ever need one.

### **Keeping in touch**

As a volunteer with York Down Syndrome Support Group we want to keep you up to date and involved in what is going on in the charity. You can ask to be added to our electronic mailing list, and you are encouraged to 'like' our Facebook page (search for York Down Syndrome Support Group) or keep an eye on our website. We may also ask for your input, knowledge and advice on matters that may not directly be to do

with your role but we value the opinions of everyone involved in York Down Syndrome Support Group.

## **Dealing with Difficulties**

### **Problems within your role**

If you ever have any issues or difficulties with anything that you are doing for us then please let us know. We are committed to listening openly to any issues you may have and to working together to resolve them. No one will be made to feel under any pressure to continue to volunteer in a role that is just not suiting them. We will always try to find something that is more appropriate.

### **Dealing with complaints**

Although dealing with complaints can be difficult, it can give us a positive opportunity to improve the way we do things and provide a better service for children with Down Syndrome. We set ourselves very high standards and we are keen to hear if we ever fall short of those standards. If you want to complain we will ensure your complaint is treated seriously, is handled without bias or discrimination and that your confidentiality is respected. Our complaints procedure can be downloaded from our website.

## Appendix 1: Terminology<sup>1</sup>

<b>Don't say</b>	<b>Do say</b>
Suffers from OR is a victim of Down syndrome	Has Down syndrome
A Down's baby/person/child	A person/baby/child with Down's syndrome or who has Down syndrome
Retarded/mentally handicapped/backward/mental disability	Learning disability
Disease/illness/handicap	Condition OR genetic condition
The risk of a baby having Down syndrome (in relation to pre-natal screening and probability assessments)	The chance of a baby having Down syndrome

<b>Myths</b>	<b>Facts</b>
People with Down's syndrome don't live very long.	Today, people with Down's syndrome are living into their 50s and 60s with a small number living into their 70s and beyond
Only older mothers have babies with Down's syndrome.	Although older mothers have a higher individual chance of having a baby with Down's syndrome, more are born to younger mothers, reflecting the higher birth rate in this group.
People with Down's syndrome cannot achieve normal life goals.	With the right support, they can. Small but increasing numbers of people with Down's syndrome are leaving home and living with support in their communities. They are , gaining employment, meeting partners and getting the best out of life.
People with Down's syndrome all look the same.	There are certain physical characteristics that can occur. Each person will have a number of the more common physical characteristics. A person with Down's syndrome will always look more like his or her close family than someone else with the condition
People with Down's syndrome are always happy and affectionate.	We are all individuals and people with Down's syndrome are no different to anyone else in their character traits and varying moods.

<sup>1</sup> Information download from the Down's Syndrome Association