

# Ask Listen Do

Making conversations count  
in health, social care and education



## Top tips for autistic people

Making feedback, concerns and complaints easier  
for people on the autism spectrum

## Welcome

This booklet is written to give people on the autism spectrum the information they need to give feedback, raise a concern or complain about health care, social care and educational services. As an autistic adult I know the difficulties we can have with feedback, concerns and complaints. It is important and our right to get our voices heard so that people who work in, manage and commission these services really understand what we are saying and what support we need.



Ask Listen Do is about making it easier for people with a learning disability, autism or both to give feedback, raise a concern or complain about their care, education or support. It is also about making it easier for family, paid carers or advocates to do this for someone they support. This can be about any aspect of the service a child, young person or adult receives in health, social care and education.

My friends and colleagues at Speakup for Autism and NHS England have helped with this booklet, and we have also talked to other autistic people to get their views. This booklet is written by autistic adults for autistic adults. This means that the top tips, stories and experience here all come from lived experience and good or bad that is the most important information.

Autism covers a wide spectrum and is different for each person, hopefully some of the advice in this booklet will work for you.

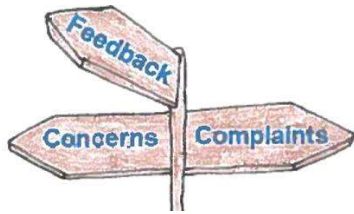


**David Gill, Speakup member  
and autism adviser with NHS England**

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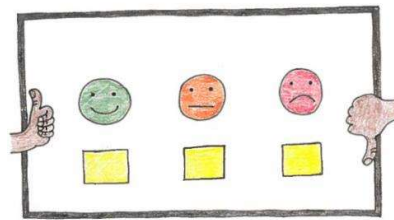
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# Feedback, Concerns and Complaints



People should feel it's OK to give feedback, raise concerns or complain. Organisations should support people to do this so they can learn from it, and improve their services for you or others.

Knowing more about giving feedback, raising a concern or making a complaint can help to make it a more positive experience.



## Feedback

This means being able to say what you like or do not like about the care, education or support you may have been given – good or bad. You can do it by talking to someone in the service or by filling in a feedback form. All feedback should always be encouraged or welcome. Organisations should ask for people's feedback and use it to improve their services. They should tell you and other people using the service how they have done this.

## Concern



You should raise a concern if you are worried or unhappy about the service you are getting. Talk or write to someone about it to see if they can sort it out straight away. A staff member can help you to do this if you prefer. Details of your concern might need to be passed on to someone else to resolve. Someone should be able to tell you quickly if or how it has been sorted out.

## Complaint



If you do not think your concern has been sorted out or you have not been listened to, you can complain. There are organisations which can help. Complaining is a formal process and organisations have a set time limit to respond in and say what they will (or won't) do. If you are unhappy with the outcome there may be more you can do, depending on the complaint and the organisation involved.

## Making reasonable adjustments

An organisation has a duty to make reasonable adjustments for people's impairments or disabilities, including autism. This means they have to change how they do things, to the best of their ability, to make it better for you.



The person you speak to may not know much if anything about autism. They may be in a rush, they might misunderstand you, it might be very frustrating trying to get your point across. But the person may know about reasonable adjustments and this can be a good way of building better communication and understanding.

The person may not ask if you've got a disability when you contact them, so tell them right at the start and say if reasonable adjustments will make it easier for you. Be specific about the reasonable adjustments you need. Then they know and can say whether and how they will meet your needs.

## Some tips about reasonable adjustments

- Know what reasonable adjustments you need, and ask for them from the start.
- Many staff will appreciate a conversation or something in writing about what your autism means for you, because autism is so different from person to person. This will help them see how personal reasonable adjustments need to be, and it'll help them work out how to adapt their services to you.
- If you need to, ask someone you trust like a friend or family member to help you to give feedback, raise a concern or complain. You can say this is a reasonable adjustment.
- Use the method of communication that works best for you and ask the organisation to use it too whenever possible. For example: email, phone, letter, or in person.
- If you find the person too hard to talk to, you could ask if there is anyone with experience of autism who could help.
- You may want to ask people to use words carefully. For example: 'take a seat' could be taken literally!
- You might ask the person to contact you at a certain time.
- For face to face meetings, ask to be seen in a quiet area if that is what you prefer.
- If you find a conversation difficult, explain this and arrange another time to talk. This will give you both time to think about how to make the next conversation better.
- It's not a reasonable adjustment as such, but whenever you are discussing your concern or complaint, it can help to write down the main things you want to say first. Remember to keep it short and to the point. Say how it makes you feel.
- Try to make written communication as concise as possible - the longer your letter is, the harder it can be for someone else to see what the issue is. Use bullet points or **bold** to show the main points, or do a short summary.

There is a two-page form with this booklet which may be useful if you want to give feedback, raise a concern or make a complaint. You should be able to use it with any service or organisation. You can download it from [www.speakup.org.uk/asklistendo](http://www.speakup.org.uk/asklistendo).

It's good to say how you feel about your health care, social care or education

**A form for your feedback, concern or complaint**

**Feedback** – when you say what you think (like if your care was good or bad), and you do not need a reply

**Concern** – if you are worried or unhappy about something and would like help to get it sorted out

**Complaint** – if your concern hasn't been sorted out and you are still unhappy, you can complain

Please tick to say which one you are writing about:

Feedback       Concern       Complaint

**Please tick one box**

I am writing about:

What happened to me

What happened to someone I support or care for

**If you want someone to contact you, or someone else, please fill in this part of the form.**

Please get in touch with me (name) \_\_\_\_\_

or \_\_\_\_\_

Please contact me by phone  email  text  letter  in person

The contact details are:

The place or service I am writing about is called: \_\_\_\_\_

What I am writing about happened on (date): \_\_\_\_\_

This is what happened:

This is what I would like to happen next:

The reasonable adjustments that will help me are:

It may help you to keep a copy of this form in case you need it again.

You can give this form to the person in charge at the place you are talking about, or post it to them.

**Your experience matters. The organisation should:**

- Listen to your feedback, concern or complaint
- Make reasonable adjustments for your impairment or disability
- If you need a response, communicate in the right way for you
- Tell you what it will do to resolve any concerns
- Respond in good time (eg. up to 21 days for a reply to a complaint)

Autism Group Visit [www.speakup.org.uk/asklistendo](http://www.speakup.org.uk/asklistendo) or [www.england.nhs.uk/asklistendo](http://www.england.nhs.uk/asklistendo) for more information about giving feedback, raising a concern or making a complaint.

## Step by step stages of concerns and complaints

**Step 1:** It's always good to sort out a concern before it becomes a complaint. Make a note of when and where it happened, what the problem is, who is involved and what would make it better. If you need it, get some advice from someone you trust. You could ask an advocacy service for help, your local Citizens Advice, or your local Healthwatch group. Talk to a member of staff or the person in charge of the service you are concerned about. Although it can be hard, try to be calm and friendly.

Ask the person how long it will take before they can give you feedback, and agree how they will do this. If you don't hear from them in this time, contact them again. If you still don't hear back or if you are unhappy with what they do, go to step 2.



**Step 2:** You can make a formal complaint. Use the word 'complaint' to make it clear it's more than a concern. The organisation will then have to follow its complaints procedure – you should find out what it is. Use your notes to remind you of what happened. Complaining can be stressful and will take time. If you are unhappy with the response, go to step 3.

**Step 3:** A large organisation may have more than one stage to its complaints process. This gives you another chance to continue with your complaint if you are still unsatisfied. You will need to explain why you disagree with what they have said and offer any other relevant or new information you can think of.

## Ombudsman services

If you are unhappy with the outcome of a complaint process, or if it is taking longer than it should, an Ombudsman may be able to help (see back page). An Ombudsman is a free and independent service, which does not take sides. You can usually ask them in writing, over the phone or online. An adviser may be able to help you better if you say what reasonable adjustments you need.

The Ombudsman will decide whether to investigate your case. The Ombudsman does not investigate every case, but if it does, it will find out more from you and the organisation involved. If the Ombudsman decides the organisation was at fault, they will say what the organisation must do to put it right. This might be an apology, or a change in the way things are done. Sometimes an Ombudsman may ask the organisation to pay you some money to make up for the problem it caused – it is usually not a lot though!

If your complaint is about a school or education service, the Department for Education has a similar role.

It can take at least several months for an Ombudsman to deal with your case. Some people find it stressful on top of any stress already caused. It may be a good idea to think about how you would deal with this and how the Ombudsman could help.



## Speakup for Autism says...



Whenever giving feedback I find that it is easier to do this in person but not necessarily to the person or service I am complaining about as I may get angry if I don't get the result I want.

**Jonathan Evans**

I am good at writing letters, so I would have little or no issue writing a letter of complaint. I find communication in person hard especially in a group of people.



**Michael Allott**



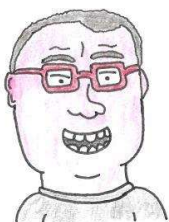
I find using email or writing a letter easier than complaining over the telephone as I can take my time and make sure I get my point across.

**David Kelly**

I find it hard to complain by email but find it easier in person. I prefer talking in person because things can be explained to me and I understand things a lot more.



**Charlie Ball**



I find it difficult to leave feedback, raise a concern or make a complaint. I am not sure of what to say and I might get upset or angry. It would help to have someone there to support me, a friend, family member, social or support worker.

**Darren Walmsley**

## Liz's Story

I rang my GP to sort out my medication and I asked the receptionist on the phone to explain how I do this. The receptionist laughed and was rude to me because I did not know what my prescription was for. I didn't feel that she explained how to get my medication properly to me. I was upset and put the phone down.

The next day I saw the nurse and I told her what had happened. She emailed this to the manager of my GP and I felt a lot better. A few weeks later I rang to make another appointment and now everything is explained properly to me. I feel that if I had not made this complaint that things would have continued the same at my Doctors.

## Jenn's Story

When my son started school the uncertainty of this created a huge amount of anxiety for me. Being autistic means that sudden change can affect my mental health if it is not handled sensitively.

Things started off badly when introducing myself with the teachers and senior leadership team. We did not get much chance to discuss adjustments before my son started in September 2016 and there was one occasion where it was reported that I was rude to a member of staff. I found it difficult in a busy hall and left with my son without being able to say what was going on when the teaching assistant asked me to stay.

My mental health deteriorated in 2017 and I was admitted to an impatient setting but after this I was able to get some support. They helped me set up some reasonable adjustments for me and this meant I was able to truly take my place within the school community and helped to support my son at times when things are difficult so he is under no pressure and that he can have a good time at school.

## For more help

### **National Autistic Society Helpline**

0808 800 4104

[www.autism.org.uk](http://www.autism.org.uk)

### **Citizens Advice**

03444 111 444

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### **Healthwatch**

0300 068 3000

[www.healthwatch.co.uk](http://www.healthwatch.co.uk)

### **NHS England Customer Contact Centre**

0300 311 2233

[www.england.nhs.uk/complaint](http://www.england.nhs.uk/complaint)

### **The Local Government and Social Care Ombudsman**

0300 061 0614

[www.lgo.org.uk](http://www.lgo.org.uk)

### **The Parliamentary and Health Services Ombudsman**

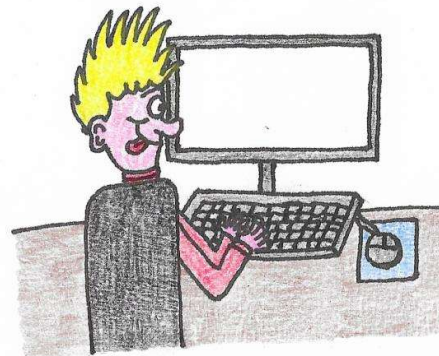
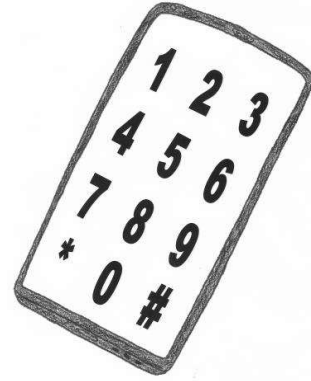
0345 015 4033

[www.ombudsman.org.uk](http://www.ombudsman.org.uk)

### **Department for Education**

0370 000 2288

[www.gov.uk/complain-about-school/state-schools](http://www.gov.uk/complain-about-school/state-schools)



## Ask Listen Do is supported by:

- NHS England
- Local Government Association
- Local Government and Social Care Ombudsman
- Association of Directors of Adult Social Services
- Parliamentary and Health Service Ombudsman
- Department for Education National Helpline
- Department for Health and Social Care
- Care Quality Commission
- NHS Improvement
- Inclusion East CIC
- Ofsted
- PBS4

**To download this booklet and a form for feedback, concerns and complaints, visit**

**[www.speakup.org.uk/asklistendo](http://www.speakup.org.uk/asklistendo)**

**Visit [www.england.nhs.uk/asklistendo](http://www.england.nhs.uk/asklistendo) for more resources for people with a learning disability, autism or both, families and professionals.**

Speakup for Autism is a self-advocacy group of people who support each other and work together as autistic adults. We have strong links with the National Autistic Society and train other organisations, health care professionals and people with autism how to communicate in a meaningful way. The group is part of Speakup Self Advocacy in Rotherham.

Many thanks to all the Speakup for Autism members who co-produced this booklet – Jonathan Evans, Charlie Ball, Michael Allott, Darren Walmsley, James Wyatt, Elizabeth Wyatt, Graeme Woodcock, David Kelly, Jodie Bradley, David McCormick and David Gill. Special thanks too to Jenn Layton, Ellie Mole, Carl Shaw, Ian Wolfenden, Maggie Graham and Sarah Jackson for your help.

Artwork by David Gill



Autism  
Group  
**Speakup**

