

POCKET GUIDE

for staff supporting

young people with

22q11.2DS



Introduction

My name is Lucy and I have 22q11.2 deletion syndrome (also known as 22q). 22q is something that you are born with which can cause problems with different parts of our bodies and our brain, and sometimes makes it hard for us to learn, remember or understand new information or instructions. It can cause us difficulty speaking and sometimes hearing too. This can make us, as young people, feel very anxious.

22q can also cause medical problems, for example with our hearts or kidneys (or both), and it can cause some of us to have fits. Some children and young people with 22q may also get infections much easier than others. Some children may use a wheelchair as their muscles aren't very strong and many will get very tired and fatigued easily.

Many of us have ADHD or Autism. This can also make us very anxious, and we may manage better by having strong routines. Things like using picture cards can help us communicate better when we are feeling stressed.

We have created this booklet to help people working in schools to better understand some of our difficulties, and to give you a few tips on how best to support us.

We hope you find it helpful,
Lucy

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My support Needs

This is a short guide for any staff supporting young people with 22q in schools, with some helpful hints and tips!

Learning support

- Young people with 22q may have different thinking and learning styles, and often need little extra support. Each young person is unique, so spend some time with them to see what works best.
- Young people with 22q may be neurodiverse and benefit from strong routines, as well as additional resources like picture cards to support communication and / or scribes; use of keyboards; pre prepared subject notes in class; or even a learning buddy.

Social and Wellbeing support

- Young people with 22q may need support with mental wellbeing and help with expressing how they feel. They will not always let you know that they are not okay, so check in with them and keep an eye on their body language.
- Young people with 22q may find friendships a little harder, so encourage inclusion with peers, both inside and outside the classroom.

Physical support

- Not all needs are visible in young people with 22q, including medical ones. Find out how these may affect their day-to-day, and if the young person may occasionally need to leave the classroom without question. For example, they may need to visit the toilet more frequently or top up their water bottle.
- The young person may be absent for medical appointments and treatments, so be sensitive to their adjustment when they return, including any need to take their medication.

Remember, *we are all unique and our voice, opinions and thoughts matter greatly.*

Actions to support me

Here are some tips on how to support me in the classroom and beyond

Supporting me to learn

- 'All about me' Information (containing educational information)
- Notes of content (subject specific)
- Picture-based (visual) maths and aids
- Electronic devices (reasonable adjustments)
- Simplified or picture-based timetables
- Seating (front or centre)
- Small group work
- Communication tools (AAC devices, MAKATON or PECS)
- Repetition and scaffolding to support working and long-term memory

Supporting my wellbeing needs

- 'All about me' information (containing wellbeing & medical information)
- Promotion of routines and support with transitions
- Traffic light system or Zones of regulations
- Social stories (young person specific)
- Fidget toys or even Blue Tac
- Access to nurture space
- Buddy systems or mentor
- Support in inclusion in peer activities

Supporting my physical needs

- Be aware that not all needs are visible including medical ones
- Check water bottles are replenished
- Be sensitive about the need to leave the classroom or take a rest break
- Fatigue may mean considering alternative, inclusive activities for PE

Additional Resources

- **MaxAppeal** is a UK charity for 22q11.2 deletion syndrome: <https://www.maxappeal.org.uk/>
You can access the full toolkit here
- **22q Ireland** is an Irish charity: <https://www.22q11ireland.org/>
They have a YouTube channel with a host of informational videos: <http://www.youtube.com/@22qIreland>
Guide for schools and teachers: <https://youtu.be/9UbBa5tWaVw?si=0Byla00FQEZqeywR>
- **22q11 Europe** is a European charity: <https://www.22q11ireland.org/>
They have a YouTube channel containing useful videos about 22q11.2 deletion syndrome: www.youtube.com/@22q11europe
- For the World Education Summit (WES) – we co-produced a video entitled Mental Wellbeing Support for Pupils with SEND: <https://weslegacy.com/sessions/100834>

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