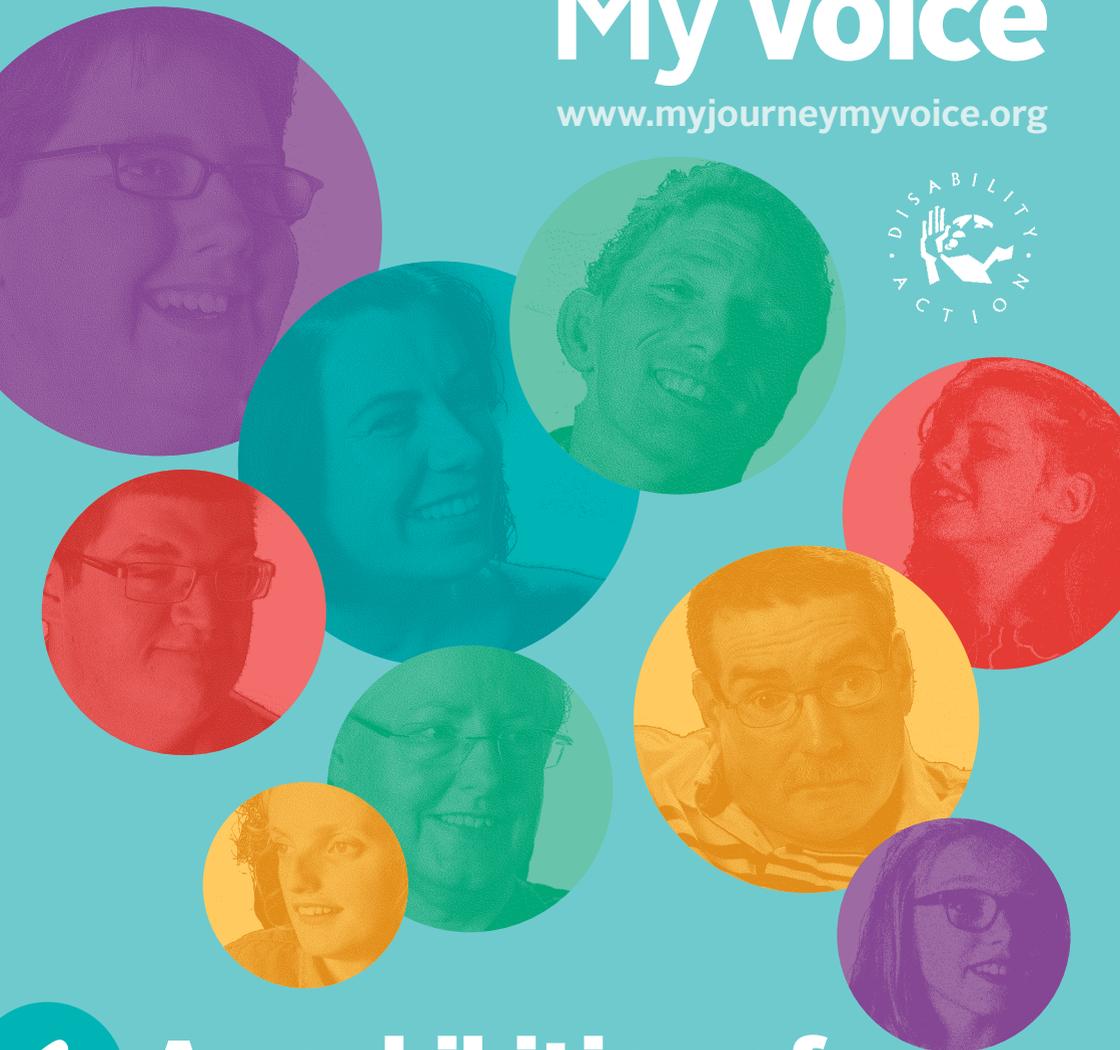




My journey My voice

www.myjourneymyvoice.org



An exhibition of portraits and stories

Raising awareness of communication disability



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www.rcslt.org



www.disabilityaction.org



FOREWORD

This portraits and stories exhibition, *My Journey My Voice*, gives us a unique and privileged insight into the lives of ordinary people who just happen to have a communication disability. Their worlds are very different to the world in which most of us live. For us, the ability to communicate is often taken for granted. For them, making an appointment, ordering a meal or chatting with a friend is something that happens with effort or cannot happen at all.

The portraits and audio recordings that make up this exhibition show them as they are; individuals with a story to tell, if only we have the time to listen. They want their voices to be heard so that all of us can better understand the diversity of communication difficulties.

Public perception of disability has shifted greatly in recent years. However, people with a communication disability still face the stigma and sometimes ridicule of those who don't know any different.

Sadly, people with communication difficulties are still more at risk of abuse than the general population. It is heartening that governments across the UK are taking heed of the findings of the recent Francis Report, 'Patients First and Foremost', which made a commitment to "listen most carefully to those whose voices are weakest and find it hardest to speak for themselves".

This exhibition, hosted in partnership with Disability Action and the Northern Ireland Health and Social Care Board, aims to provide a useful training resource for government and the public and private sectors. It will enable everyone who experiences it to have a greater insight into the nature and impact of communication disabilities.

Finally, we wish to acknowledge that none of this would have been possible without the courage and commitment of our participants and their families in allowing their faces to be seen and their voices to be heard. We also wish to thank our members and Mr Laurence Gibson for facilitating the photography and recording sessions.

Alison McCullough MBE
Head of Northern Ireland Office
RCSLT



Anne Gamble
Northern Ireland Country Representative
RCSLT

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The *My Journey My Voice* exhibition will be touring various venues around Northern Ireland raising awareness of communication disability.

Details of the tour will be available on the *My Journey My Voice* website:
www.myjourneymyvoice.org

If you would like to learn more about communication disability or if you would like to use the *My Journey My Voice* experience for training in your organisation, contact the RCSLT: 02890446387 or janet.mcgookin@rcslt.org or contact Disability Action: www.disabilityaction.org



HOW TO USE THIS BOOKLET

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his booklet provides information about the individuals participating in *My Journey My Voice*. Inside, you will find profiles of each of the

participants alongside their portrait. These are accompanied by a description of their communication difficulty and how speech and language therapy helps support them.

There is also a short excerpt taken from each participant's audio recording. These recordings were integral to the project as they give us an opportunity to hear from the individuals themselves. Each recording is very different as each of our participants have varying degrees of communication difficulty. Some need others to speak for them because they cannot speak for themselves, some use stand-alone voice output devices and some use computerised voice output software. Some use vocalisations which may be difficult for

anyone other than their family members to understand. Some supplement their vocalisation with a combination of voice output devices and signing programmes like Makaton.

In the recordings, some of our participants take the opportunity to talk about their communication difficulty while others simply tell a story from their life. You may hear and read the excerpts from them having a conversation or being assisted with their communication by someone else, for example, a parent or carer.

This booklet can be used in conjunction with our touch screen voice playback units or with a QR code app. (A full explanation of how to download the QR code reader onto your smart phone is on page opposite.)

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LISTEN TO THEIR STORIES



How to download a QR reader app onto your smartphone and use the QR codes



STEP 1

Download and install a QR code app on your smartphone if you don't yet have one. Open your App Store, Market, Marketplace or App World application (for the iPhone, Android, Windows Mobile and BlackBerry platforms respectively).



STEP 2

Search for "QR code reader," and then download and install a free app. The app should be named something to the effect of "QR Code Scanner" or "QR Scanner." There are paid versions of these kinds of apps, but the free ones work just as well.



STEP 3

Open the QR barcode app on your smartphone, and choose "scan from camera" or "scan QR code" from the main menu. A new window should open with a square in the middle of it.



STEP 4

Center the QR code in the middle of the square that's currently displayed by your QR barcode app. The app should automatically take a picture of the QR code for you when it has finished scanning the code. A new pop-up menu will appear, with the QR code information on it.



STEP 5

Click the link that was embedded in the QR code if there is one. This will direct you to the *My Journey My Voice* mini website for that participant where you can read or listen to their story.



GEORGE

George is 37 and has cerebral palsy, a neurological condition that affects his posture, muscles, coordination and movement. George's cerebral palsy also affects his speech because he has difficulty controlling his tongue, breathing and vocal cords. As a result, George has profound communication difficulties that affect all aspects of his daily life.



What speech and language therapy does for George

George's speech and language therapists have enabled him to communicate more successfully and independently by teaching him to work with two devices. The first, an E-Tran, is a device which allows George to use his eyes to gaze at symbols to communicate. The second, a Big Mack switch, is a large button that George can press to speak a recorded message, for example 'yes'. Using these devices allows George to participate in more situations and interact with others.

→ Examples of symbols similar to the ones George uses to communicate



In George's words

George's story is told by his care worker on a recorded device as George is only

able to vocalise one word: 'Aye'.

"I went on a bus trip to Newcastle with the Rowan Centre a couple of weeks ago. In Newcastle we went for a walk along the prom and then we got lunch. I really enjoyed the trip and the best part of it was I had ice cream. I like being able to go out with the Rowan Centre and have fun."

Here, Alison McCullough, head of RCSLT NI office, is in conversation with George.

Alison: Are you living with your brother at the minute?

George: Aye.

Alison: At home?

George: Aye.

Alison: Do you like going out on trips?

George: Aye.

Alison: Have you been to Newcastle?

George: Aye.

Alison: Now you are in Belfast?

George: Aye.

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JEMIMA



Jemima has had a physical disability since birth. She is now 16 and has had severe speech, language and communication difficulties her whole life as a result of her disability.

Jemima understands language well, but has difficulty expressing herself. She mostly uses sounds and facial expressions to communicate which works well with her close family and friends, but not as well with people who don't know her. People often underestimate Jemima because she cannot communicate easily. She finds this very upsetting.

Jemima also uses a communication device to assist her communication.



What speech and language therapy does for Jemima

Jemima's speech and language therapist introduced sign and symbol communication systems when Jemima was very young to encourage her communication skills. Giving Jemima a way to interact with others and make her own choices motivated her to continue working on her communication skills.



In Jemima's words

Jemima uses vocalisations and a voice output communication device to chat. Here, Jemima is in conversation

with her mum and Alison McCullough, head of RCSLT NI office.

Alison: Is there a special place that you have been to that you want to tell us about today?

Mum: You could always tell them about your last holiday and who you met.

Jemima vocalises and types on her device: South America, no, Africa.

Alison: Goodness on a holiday, wow, and you went over with your mum and dad and did you meet somebody?

Jemima: Aye, yeah, Sean, Africa, Sean Penn.

Alison: Sean Penn, my goodness, the film star, wow, what does he look like, is he good looking?

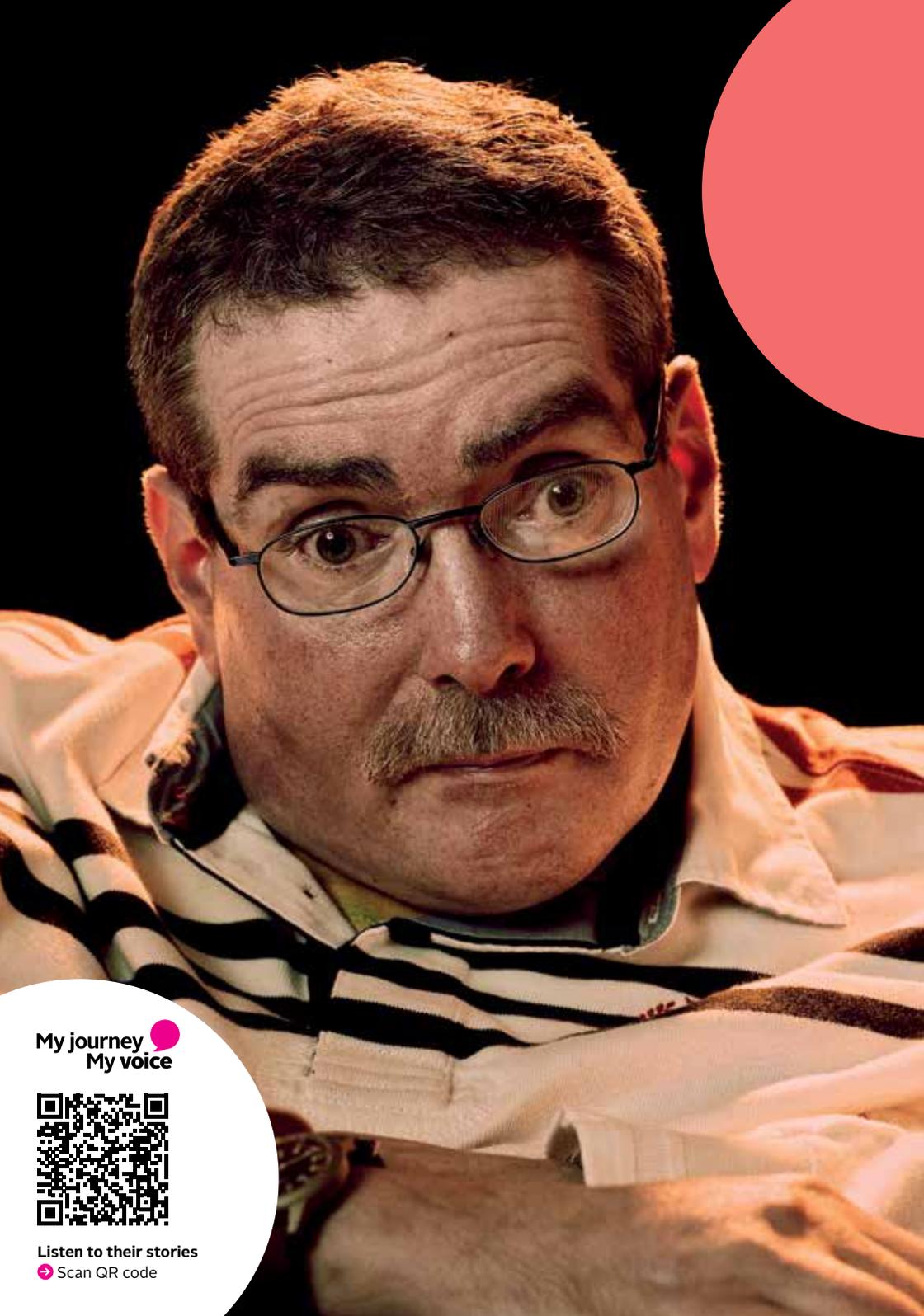
Jemima: Yeaahhhhhh.



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NEILL

Neill is 47 and has secondary progressive multiple sclerosis, which affects his brain and nervous system. Over time, he has lost the ability to control his muscles, including those he uses to speak.



What speech and language therapy does for Neill

Neill's speech and language therapist has helped him to use communication software on his computer, which he controls using a head switch, so that he can communicate through writing.

"My communication device has afforded me the opportunity to not only write but also send emails and to shop online. I'd be lost without it," says Neill.

"I have received confirmation that funding for a new device has been granted. This new device will allow me to control simple things like turning a TV on and off. The positive effects to my health and self-esteem can only be imagined. I cannot emphasise enough how important it is to give the speechless a voice!"



In Neill's words

Neill uses a voice output device. He has to type out each word letter by letter

and then play the recorded word or phrase. Neill uses the device to tell about his road trip through America with his father.

"I remember a sunny July day in 2001. I had been teaching for a month in North Carolina and had finally persuaded my father to fly out and join me. We had been touring extensively by car and we were now in Front Royal Virginia, the gateway to the Smoky Mountains and Skyline Drive.

"We stopped at a lay by to take some photographs. We were very lucky with the combination of the light and the atmospheric. It was the single most stirring sight either my father or I had ever seen. It left us wrapped in our own thoughts. Sometimes it is better just to share the moment and not to spoil it by talking."

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CLODAGH

Clodagh is 36 and recovering from a stroke. At first, her stroke caused her to be 'locked-in'. Although she was conscious and able to hear and think normally, she was completely paralysed and unable to talk or move.

"It was the most horrendous thing in my whole entire life not being able to communicate," says Clodagh.

While recovering, Clodagh has been learning to speak again. But damage to the muscles in her mouth and face have made her breathing difficult and her speech sound nasal, slurred and quiet - very different to before her stroke.



What speech and language therapy does for Clodagh

Following her stroke, Clodagh's speech and language therapist taught Clodagh and her family a way to communicate with each other. This included teaching Clodagh to use her eyes to 'point' to pictures, words or symbols or blink to spell out words.

As Clodagh regained her speech, her therapist provided exercises to strengthen the muscles Clodagh uses to talk. "Now I talk to everyone with my new voice. I absolutely love talking!" says Clodagh. But it's not always easy, she says, "I find when I am out, people choose to talk to my family or my partner and that frustrates me because I can talk even though I sound different."



In Clodagh's words

"Before Easter Monday I was fit and healthy and then on Easter Monday I took a slightly sore neck and then a fuzzy head and then I went to hospital by ambulance. After waiting there for some length of time, I had a massive brainstem stroke.

"I'm still in hospital. I was admitted on the 6 of April and it is now July and I'm probably going to be there for a few more months. When I woke in the Royal I was in intensive care and I felt completely normal, although I couldn't move or talk and I had no means of communicating to my family and friends. So for two weeks or so I had a lot to say but I had no means of communicating.

"At the start in the Royal, my sister said one of the most fearful things she had ever endured in her life was to watch me making a silent cry, a cry with no noise. So once I could make noise, she said it was wonderful even though I cried, to hear me crying with noise."



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MARGARET

Margaret is 59 and has aphasia, an acquired language disorder resulting from neurological damage caused by a stroke. It is a life-long, life-changing condition that affects both Margaret and those close to her.

Margaret has difficulties processing and understanding verbal and written information, and can struggle with spelling and finding sounds and words when talking.

“It has been so traumatic from day one of having my stroke. Before it was so special in that everything, every day was easy overall, then straight after the stroke we had a period of everyday was blank.”



What speech and language therapy does for Margaret

Margaret’s speech and language therapist works closely with Margaret, her family and carers to teach them how to make communication easier. This includes providing information in a way that Margaret can easily understand and giving her time to respond.

“Living with aphasia, life can be complicated. It is challenging to use the phone, challenging to read letters, make appointments. Every day there are barriers,” says Margaret. “Six months ago it was awful but today it is tolerable, I have adjusted and improved.”

“I am a nursing sister and I am finding it useful being in this position as a patient who is aphasic,” says Margaret. “I can see the benefits of speech and language therapy in my journey of recovery.”



In Margaret’s words

Margaret has word finding difficulties. Here, she is in conversation with Alison

McCullough, head of RCSLT NI office, with the assistance of her husband, Bobby.

Margaret: For two days I no idea what was happening to me. It was so strange, so uncouth. I remember waking up and seeing Bobby sitting on the side of the bed and he was strange looking and I put my head down and I no idea what else feeling.

Alison: Were you able to speak at that point?

Margaret: No.

Alison: And Bobby, were you able to communicate with her at all?

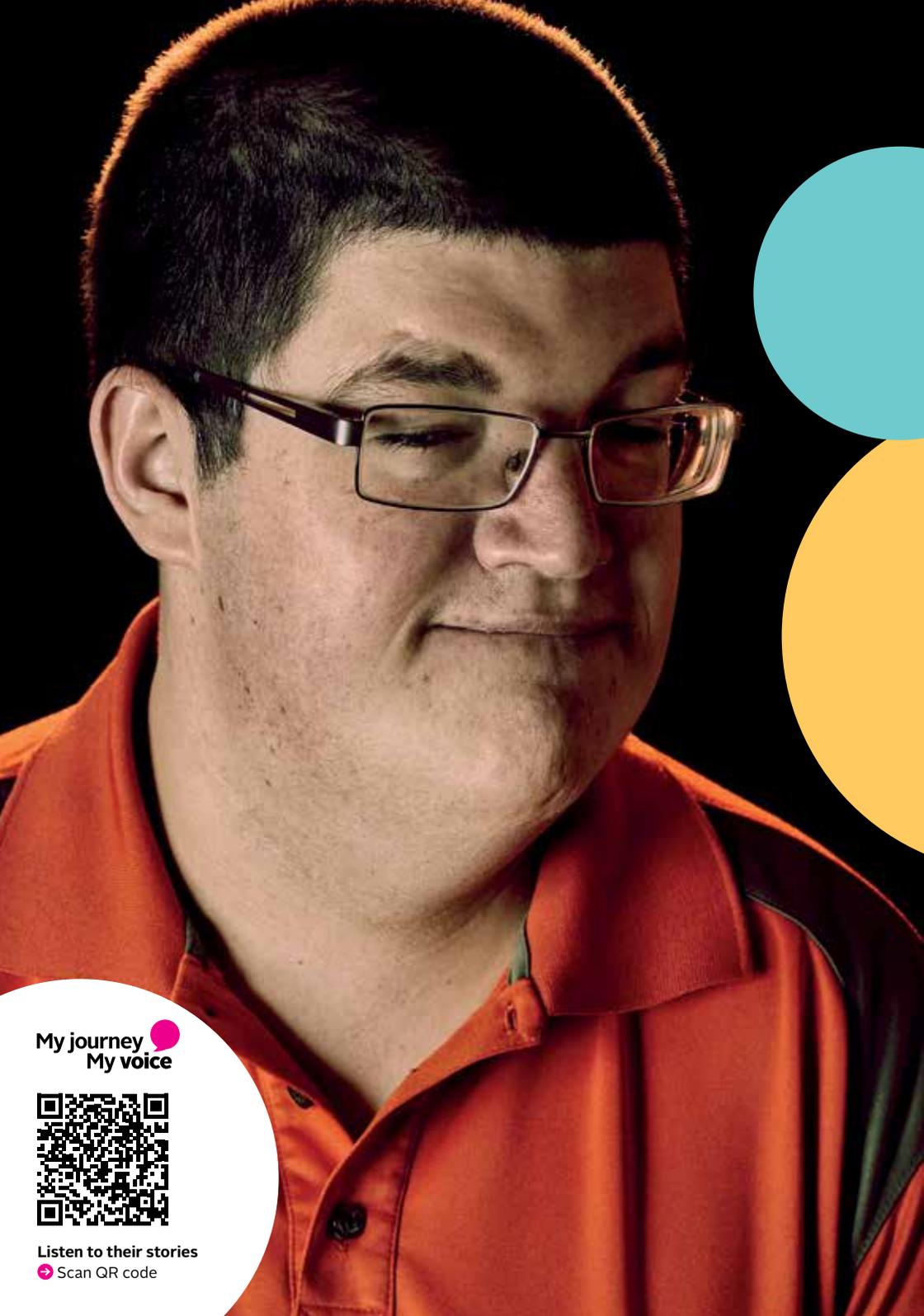
Bobby: Not really. I think the only thing she did in that first two weeks was she put her left hand up and did one of my buttons up because it had become undone.

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RYAN

Since birth, Ryan has had a learning disability which has affected his ability to speak, understand language, learn new skills and cope independently.

Ryan is now 34 and his severe communication difficulty can lead to frustration and isolation as he struggles to get his meaning across. He finds it upsetting if people cannot understand him or do not take the time to try and interpret his message.



In Ryan's words
Here, Ryan uses vocalisations, Makaton and a lightwriter communication device to tell a story about going to get a new puppy to Alison McCullough, head of RCSLT NI office. Ryan's Dad offers assistance.

Ryan: Portadown. Portadown.
Alison: So you went to Portadown to get Ben [the puppy]. How did you choose Ben?
Ryan replies using his lightwriter: Were fat. Were fat.
Alison: You picked out the little fat one? What colour was he?
Ryan: Brown. Brown.
Alison: Brown all over or any spots?
Ryan: One. On face.



What speech and language therapy does for Ryan

Ryan's speech and language therapists have taught him to use Makaton, a language programme that uses signs and speech and symbols. They have also guided him in using other communication devices, such as picture books and a computerised voice, to support him in communicating.

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MOLLY



Molly was born profoundly deaf, but now, with her cochlear implant she can hear some sound.

Molly doesn't always "get" the more subtle aspects of language, such as colloquialisms and jokes. She is now 12 and can feel isolated from her peers because she has trouble joining in their conversations and activities. Molly also finds it challenging to sustain good listening skills and her hearing loss often has an impact on her school work.

Molly used to use British Sign Language along with speech but now only uses speech to communicate.



What speech and language therapy does for Molly

Molly's speech and language therapist has worked with Molly and her parents to develop her communication by helping her understand and use language as well as working on the pronunciation of sounds.

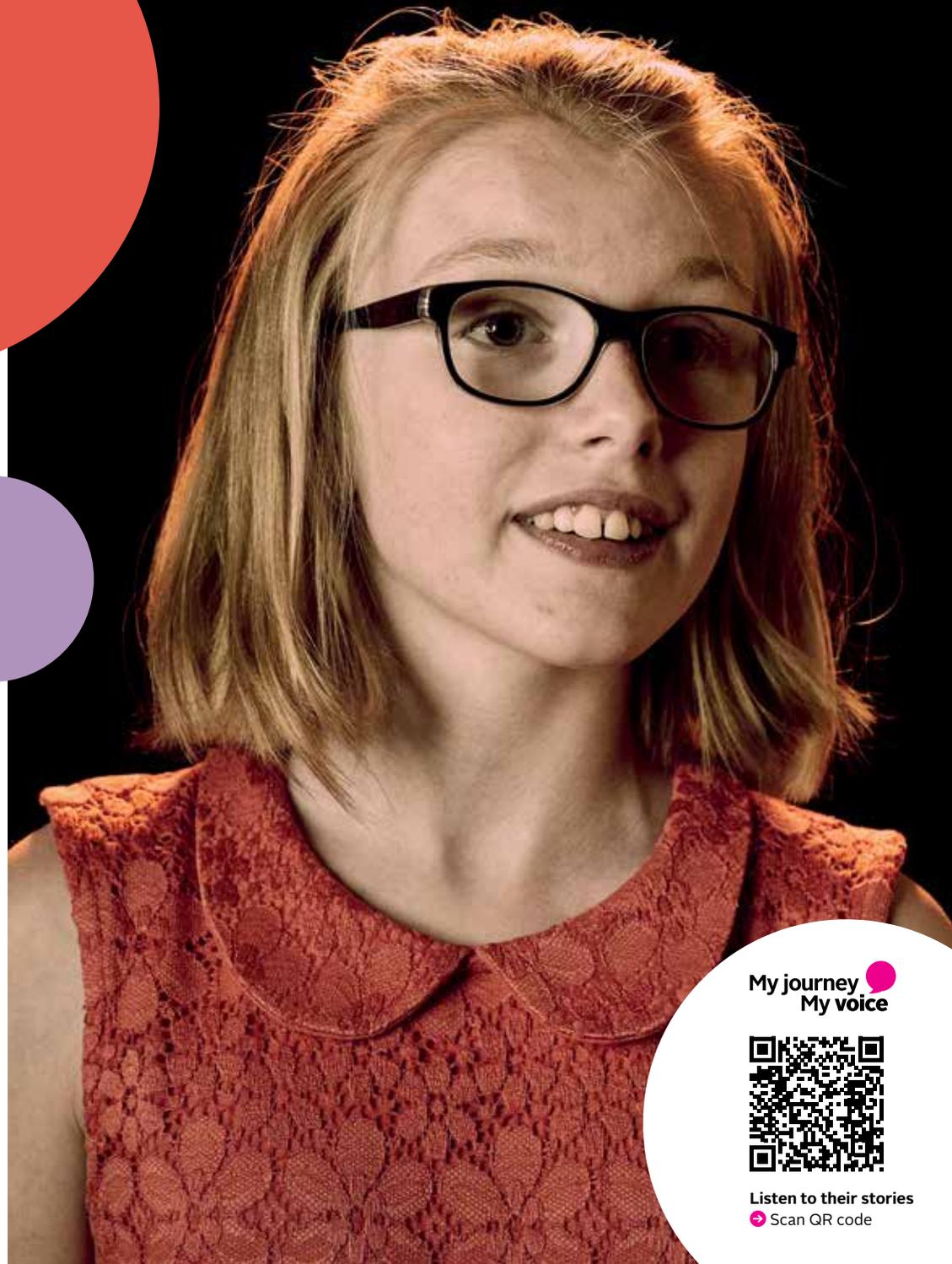
Molly's father says, "Speech and language therapy has helped Molly to make friends at school and enjoy more activities at home because she can now talk."



In Molly's words

"On Monday morning, me and my family got organised for a summer holiday. Our hotel was very close to the Dublin airport. You see my cousins, the Leonards, came with us as well. We took a bus to the airport. When we got on the bus, we took on the plane, I mean, when we got on the plane.

"It took about three and a half hours. When we got into Barcelona, it felt very hot like the air was very hot and I was very excited as I never experienced such heat. When we went into Villa Nova, we left our cases in our mobile home and headed straight for the pool."



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CHRISTINE

Christine is 22 and has a stammer. It causes her to sometimes repeat words, prolong parts of words or sounds or 'freeze' on some words.

"My stammer has proven to have had a knock on effect on my ability to communicate on various different levels," says Christine. "Making friends at school was one of the first barriers that I encountered, resulting in being a victim of bullying throughout my 12 years at school."



What speech and language therapy does for Christine

Christine's speech and language therapist works with her to give her a better understanding of her stammer and help develop strategies she can use to enhance her flow when talking, for example, speaking in a slower, easier way.

"Since starting speech and language therapy in February 2013, I have 'found' my voice. By no means is my stammer gone, but it is nothing that cannot be challenged through a slow, relaxed, and gentle approach to words," says Christine.

Ultimately, speech and language therapy aims to help Christine say what she wants to say with less anxiety and fear.

"Every day is a different one, with different challenges," says Christine. "I feel that those difficulties have enabled me to overcome communication barriers and strengthened me as a person."



In Christine's words

"One day I had a phone call from Sharon McEvoy [a friend through the British Stammering Association] in London. She asked if I would go to London to stay in her house for the weekend. It was the best weekend ever. A lot of things happened that weekend from travelling, touring, chatting to drinking tea."

"In the weeks leading up to the weekend I started to get anxious and I remember talking to Mary [Christine's speech and language therapist] about it. I didn't sleep. The excitement was just building and I remember walking down to the boarding gate and I remember asking myself one question: is it too late? But I knew it was far too late and I couldn't turn back so I boarded and flew on. I was greeted with the biggest hug and biggest kiss ever."

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OLIVIA

Olivia is six-years-old and has an autistic spectrum disorder. It is a life-long, complex developmental disability affecting her communication and social skills. Olivia has difficulty making sense of the world around her and in relating to other people.



What speech and language therapy does for Olivia

Olivia's speech and language therapist works closely with Olivia, her family, and her school to identify the signs and pictures Olivia needs to help her communicate effectively with her peers and others.

Her therapist has also assessed Olivia's understanding of language and is helping to develop this by implementing strategies for those who are communicating with her, for example, breaking instructions up into stages, placing emphasis on key words, and using a sign or gesture to help her understand.

Olivia's speech and language skills have developed significantly with the help of a speech and language therapist. Her speech may still be unclear to people who are not familiar with her, so she uses signs and pictures or a symbolic sound (eg, brmm, brmm to signify a car) when people don't understand her.

Olivia has become much less

frustrated as her communication skills have improved and she is now more willing to attempt to communicate with those around her. Her behaviour has also improved and her carers believe this is linked to her improved language skills.



In Olivia's words

Olivia uses mostly simple phrases to talk. Here, she talks with her mum about their holiday to Legoland.

Mum: Where did we go when we went on our holidays?

Olivia: Went to Nanny's house.

Mum: Where did we go when we got to nanny's house?

Olivia: Aeroplane.

Mum: We went on the aeroplane. Did we go anywhere special?

Olivia: Yes.

Mum: We went to Legoland and what did we do at legoland?

Olivia: Had lunch.

Mum: Did we go on any rides?

Olivia: Yes, slide, weeeeeeeee.

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FURTHER INFORMATION

Further information on types of communication disability and forms of Alternative and Augmented Communication can be found here:

Royal College of Speech and Language Therapists

Arthur House
41 Arthur Street
Belfast BT1 4GB
Tel: 02890 446 385
Email: alison.mccullough@rcslt.org
www.rcslt.org
www.givingvoiceuk.org

The Communication Trust

Unit 31
Angel Gate
Goswell Road
London EC1V 2PT
Tel: 0207 843 2526
Email:
enquiries@thecommunicationtrust.org.uk
www.thecommunicationtrust.org.uk

Communication Matters

Leeds Innovation Centre
103 Clarendon Road
Leeds LS2 9DF
Tel & Fax: 0845 456 8211
Email:
admin@communicationmatters.org.uk
www.communicationmatters.org.uk

Disability Action

Head Office - Belfast
Portside Business Park
189 Airport Road West
Belfast BT3 9ED
Tel: 028 9029 7880
Textphone: 028 9029 7882
Fax: 028 9029 7881
Email: hq@disabilityaction.org

Mencap

The Northern Ireland
Segal House
4 Annadale Avenue
Belfast BT7 3JH
Tel: 028 9069 1351
Learning Disability Helpline
Tel: 0808 808 1111
Email: helpline.ni@mencap.org.uk
www.mencap.org.uk/northern-ireland

Action on Hearing Loss

Harvester House
4 - 8 Adelaide Street
Belfast BT2 8GA
Tel or textphone: 028 9023 9619
Text answerphone: 028 9031 2033
Fax: 028 9031 2032
Email:
information.nireland@hearingloss.org.uk
www.actiononhearingloss.org.uk

ADD-NI

Children's Charity, Northern Ireland
Attention Deficit & Hyperactivity Disorder
86 Eglantine Avenue
Belfast BT9 6EU
Tel: 02890200110
Fax: 02890200112
Email: hello@addni.net
www.addni.net

Alzheimer's Society

Unit 4 Balmoral Business Park
Boucher Crescent
Belfast BT12 6HU
Tel: 028 9038 7771
Email: nir@alzheimers.org.uk
www.alzheimers.org.uk

Autism NI

Donard
Knockbracken Healthcare Park
Saintfield Road
Belfast BT8 8BH
Tel: 028 9040 1729
Fax: 028 9040 3467
Email: info@autismni.org
www.autismni.org

British Deaf Association

Email: bda@bda.org.uk
Tel: 020 7697 4140
SMS/FaceTime: 07795 410 724
ooVoo/Skype: bda.britdeafassoc
www.bda.org.uk

Carers Northern Ireland

58 Howard Street
Belfast BT1 6JP
Tel: 02890 439 843
Email: advice@carersuk.org
www.carersuk.org/northernireland

Multiple Sclerosis Society

MS Society Northern Ireland
The Resource Centre
34 Annadale Avenue

Belfast BT7 3JJ
Tel: 02890 802 802
Email: helpline@mssociety.org.uk
www.mssociety.org.uk

National Deaf Children's Society

Northern Ireland office
38 - 42 Hill Street
Belfast BT1 2LB
Tel: 028 9031 3170
Fax: 028 9027 8205
Text: 028 9027 8177
Email: nioffice@ndcs.org.uk
www.ndcs.org.uk

Northern Ireland Chest Heart and Stroke

Belfast Office
21 Dublin Road
Belfast BT2 7HB
Tel: 028 9032 0184
Email: mail@nichs.org.uk
www.nichs.org.uk

The British Stammering Association

15 Old Ford Road
London E2 9PJ
Tel: 020 8983 1003
Fax: 020 8983 3591
Email: mail@stammering.org
www.stammering.org

The Cedar Foundation, A better future for people with disabilities

Head Office
Malcolm Sinclair House
31 Ulsterville Avenue
Belfast BT9 7AS
Tel: 028 9066 6188
Email: info@cedar-foundation.org
www.cedar-foundation.org

Belfast Health and Social Care Trust

Making Communication Accessible for All:
A Guide for Health & Social Care Staff
<http://tinyurl.com/86jyb3a>

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