

# Speak Out For Change Experience Survey

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**Speak Out for Change – understanding how living with a neurological condition or caring for someone with a neurological condition affects quality of life.**

## Introduction

At least 48,000 people in Northern Ireland are living with a neurological condition and many more people are caring for someone with a neurological condition. With this in mind we have developed the Speak Out For Change Experience Survey for Northern Ireland.

There are a wide range of neurological conditions affecting people of all ages in their day-to-day lives – affecting the emotional, physical and social aspects of daily living.

Whether you are an adult or a young person living with a neurological condition, or a partner, care giver, son, daughter, relative or friend, we would like you to share your experiences and the impact on your family. You will help us to understand how a neurological condition affects every aspect of your daily life so that we can work to ensure that existing services in Northern Ireland meet your needs.

## How to take part

1. Describe a real experience that happened to you, to a family member or someone you know by typing it into the website or writing it down on paper.
2. You will be given a set of questions (in the form of triangles) on the sheet of paper you've been given. Please contact Julie Mawhinney, tel 02890 321313, email [neurological.conditions@hscni.net](mailto:neurological.conditions@hscni.net) who will provide you with posting instructions.
3. Answering these questions will tell us what YOU think or feel about your experience.
4. Provide some background information below to help us compare the experiences of different groups of people.

## Which of the following best describes you?

- |  |   |
|--|---|
| <input type="checkbox"/> An adult living with a neurological condition       | <input type="checkbox"/> A family member of someone with a neurological condition |
| <input type="checkbox"/> A young person living with a neurological condition | <input type="checkbox"/> A friend of someone with a neurological condition        |
| <input type="checkbox"/> A carer of someone with a neurological condition    | <input type="checkbox"/> Other: _____   |

# Speak Out For Change Experience Survey

## Project Contact Details

If you have any queries about completing this survey please contact Julie Mawhinney, Public Health Agency, tel 02890 321313, email ([neurological.conditions@hscni.net](mailto:neurological.conditions@hscni.net)).

If you require this document in an alternative format (such as large print, Braille, disk, Easy Read, audio file, audio cassette or in minority languages to meet the needs of those not fluent in English) please contact : [neurological.conditions@hscni.net](mailto:neurological.conditions@hscni.net)

You can find out more about the project by following the link <http://www.publichealth.hscni.net/ncnsurvey>.

## Support

You may find that it helps for you to have someone to talk to about your responses to the questions – a friend or family member, or someone who provides you with support or services.

If you wish to find out more about support or have other queries, the following organisations may be of help:

- Alzheimer's Society – Tel: 028 9066 4100, Email: [nir@alzheimers.org.uk](mailto:nir@alzheimers.org.uk)
- Association for Spina Bifida and Hydrocephalus – Tel: 01733 555 988, Email: [niro@asbah.org](mailto:niro@asbah.org)
- Ataxia UK – Tel: 0845 644 0606, Contact name: Alex Duncan, Email: [alexsduncan@hotmail.co.uk](mailto:alexsduncan@hotmail.co.uk)
- Brainwaves NI – Tel: 028 9335 3995, Email: [brainwavesni@hotmail.com](mailto:brainwavesni@hotmail.com)
- Carers NI – Tel: 028 9043 9843, Contact name: John McCormick, Email: [john.mccormick@carersni.org](mailto:john.mccormick@carersni.org)
- Child Brain Injury Trust – Tel: 028 9081 7145, Contact name: Lila Yates, Email: [lilayates@cbituk.org](mailto:lilayates@cbituk.org)
- Epilepsy Action – Tel: 0808 800 5050, Email: [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)
- Headway – Tel: 0808 800 2244, Email: [helpline@headway.org.uk](mailto:helpline@headway.org.uk)
- Huntington's Disease Association – Tel: 028 2177 1812, Contact names: Errol Walsh or Christine Collins, Emails: [errol@hdani.org.uk](mailto:errol@hdani.org.uk) or [Christine\\_collins@mailforce.net](mailto:Christine_collins@mailforce.net)
- Motor Neurone Disease Association of Northern Ireland – Tel: 028 9334 2040, Email: [mndani@hotmail.co.uk](mailto:mndani@hotmail.co.uk)
- Multiple Sclerosis Society – Tel: 028 9080 2802
- Muscular Dystrophy Campaign – Tel: 0800 652 6352, Email: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org)
- Northern Ireland Campaign for ME/CFS Healthcare – Tel: 028 9047 2322, Contact name: Lesley Rooney, Email: [Lesley.rooney@ymail.com](mailto:Lesley.rooney@ymail.com)
- Patient Client Council (PCC) – Tel: 0800 917 0222, Contact name: Richard Dixon (Local Area Manager), Email: [Richard.Dixon@hscni.net](mailto:Richard.Dixon@hscni.net)
- Parkinson's UK – Tel: 028 9092 3370
- Progressive Supranuclear Palsy (PSP) Association – Tel: 028 7135 8499, Contact name: Sandra Campbell (Development Officer for Northern Ireland and Ireland), Email: [Sandra.campbell@pspeur.org](mailto:Sandra.campbell@pspeur.org)
- Syringomyelia Arnold Chiari Association – Tel: 07826 004 008, Email: [saca.info@yahoo.co.uk](mailto:saca.info@yahoo.co.uk)

# Speak Out For Change Experience Survey

## **Confidentiality**

Thank you for taking part in this exercise. The information you have shared in this survey is anonymous and untraceable. When contributing your experiences, please do not provide the names of family members, caregivers or professionals.

All information will be handled and stored in accordance with the Data Protection Act 1998. By completing and returning the survey you are consenting for your anonymous information to be used with that of others in the development of a study report.

The findings of the exercise will help those planning and lobbying for services to understand the effects of neurological conditions on people's lives and consider how services can meet their needs.

# Speak Out For Change Experience Survey

Imagine you were trying to help someone understand the day to day challenges which someone who lives with a neurological condition faces or you as a carer face to show them how it impacts on your quality of life.

What experience or event would you tell them about to help them appreciate the challenges faced by you or a someone who cares for a person with a neurological condition?

The experience that you share should describe something that has actually happened to you in the last 2 years. Write as little or as much as you wish. Do not worry about spelling or grammar. We just want to know about your experience. Please do not provide the names of family members, caregivers or professionals.

**If you were to give your experience a title, what would it be? (eg what is the lesson we can learn from this story)**

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**Please list 3 words that describe best how you felt about this experience:**

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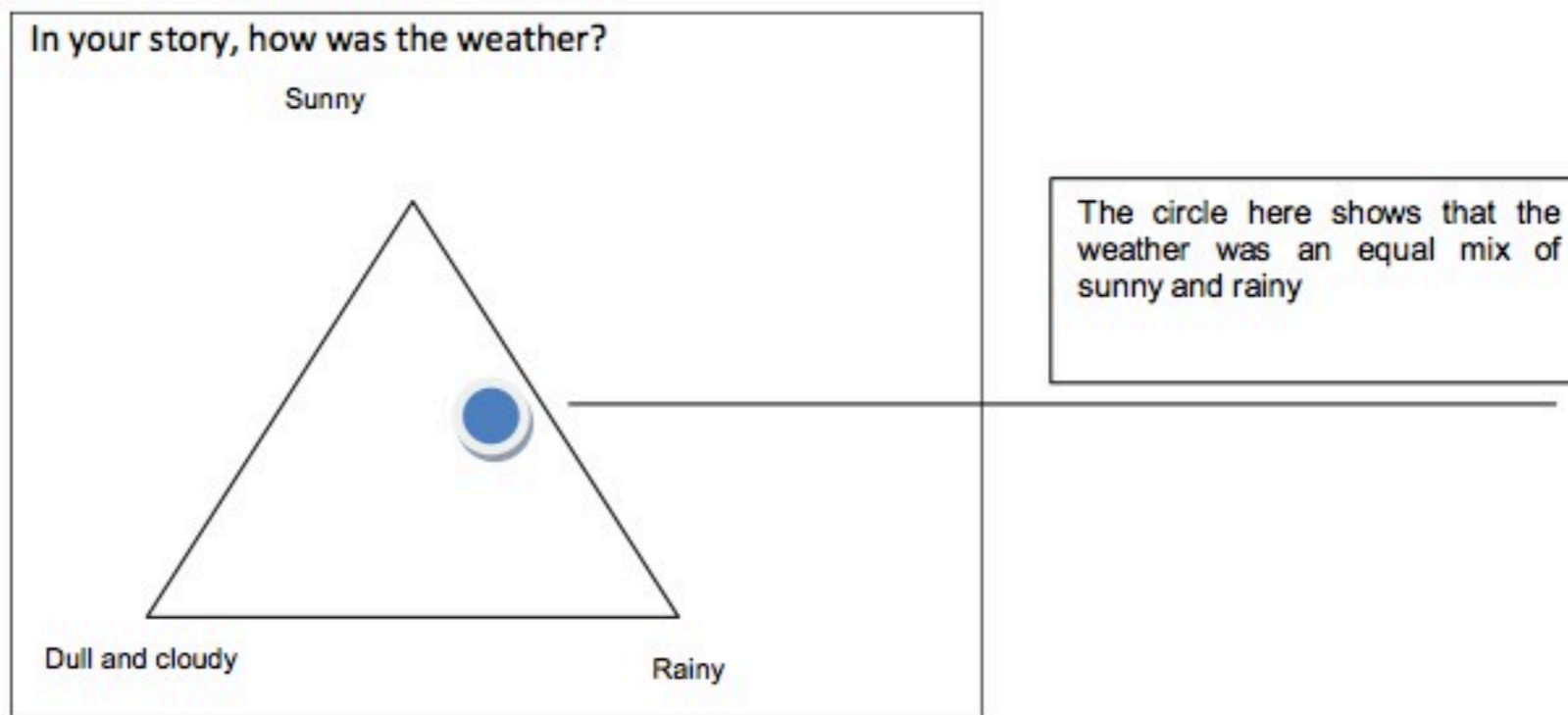
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# Speak Out For Change Experience Survey

Please answer the questions and mark the spot on each triangle using the mouse/circle which best reflects the experience in your story. You may put your circle anywhere within the triangle to show whether your answer relates to one specific point or is a mixture of two or three points.

Example:

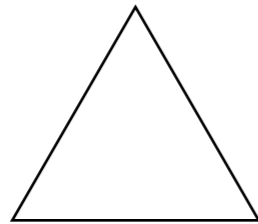


# Speak Out For Change Experience Survey

Please answer the questions by marking the spot on each triangle which best reflects the experience in your story. If any are not applicable, indicate N/A.

**1. In your story, how were you able to manage getting out and about?**

Independently – due to adaptations, aids and technology



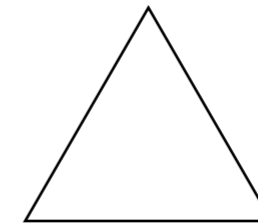
I relied on others for assistance

I can't get out

N/A

**2. In your story, what made the most important contribution to help you meet your physical needs?**

Diagnosis and timely co-ordination of medication, treatment and support for this stage of my condition



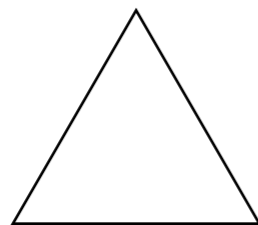
Information to help me fully understand the symptoms and impact of the condition

N/A

Being able to find and use the range of available services to meet my needs including respite

**3. In your story, how well were you able to express yourself and convey your wishes?**

I was able to fully express myself so that people understand



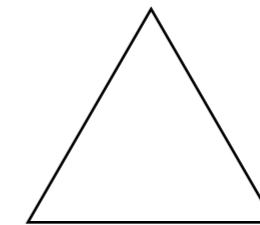
My wishes tended to be misunderstood

I had to use others as 'my voice'

N/A

**4. In your story, to what extent did you feel treated as a unique person in your own right?**

Not at all – I feel that others only see the condition and not me



I'm free to express my individuality and preferences

I've changed – I'm not sure who I am any longer

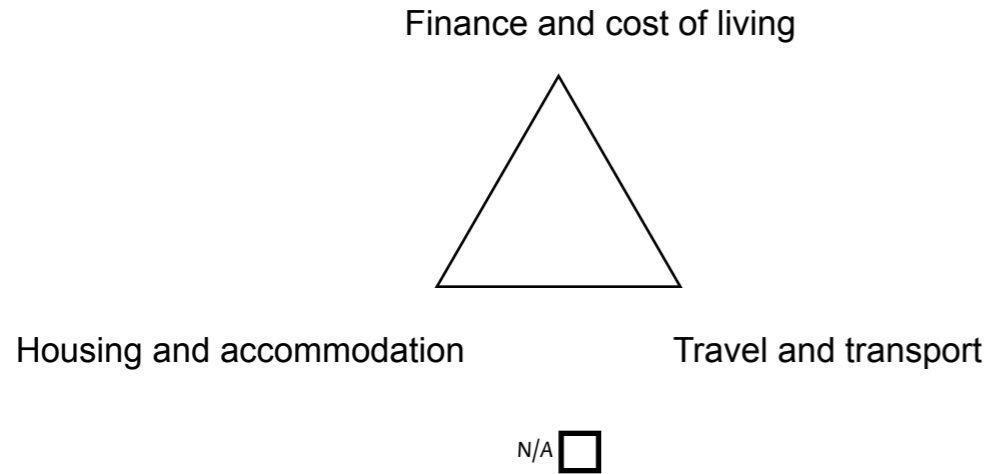
N/A



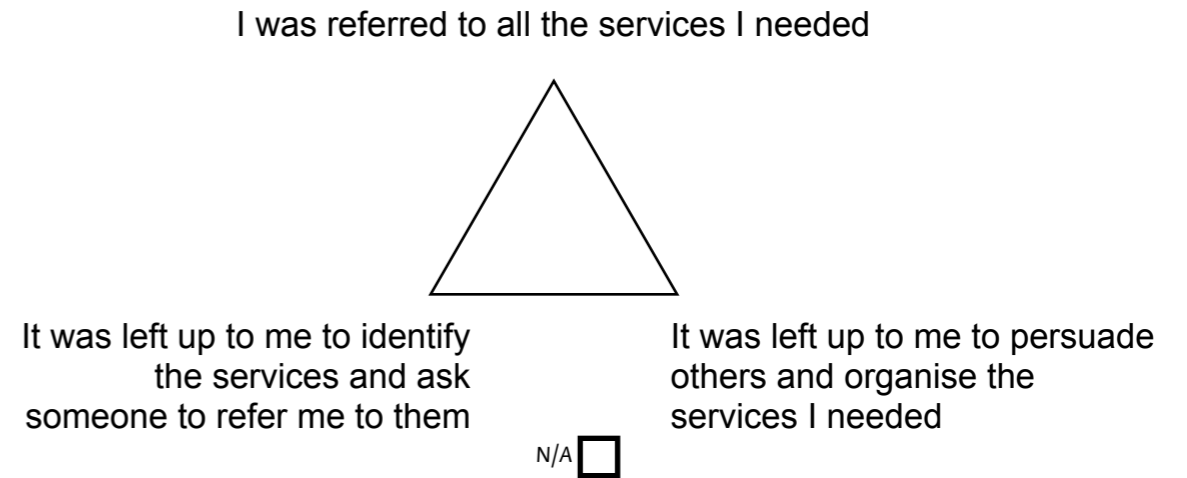
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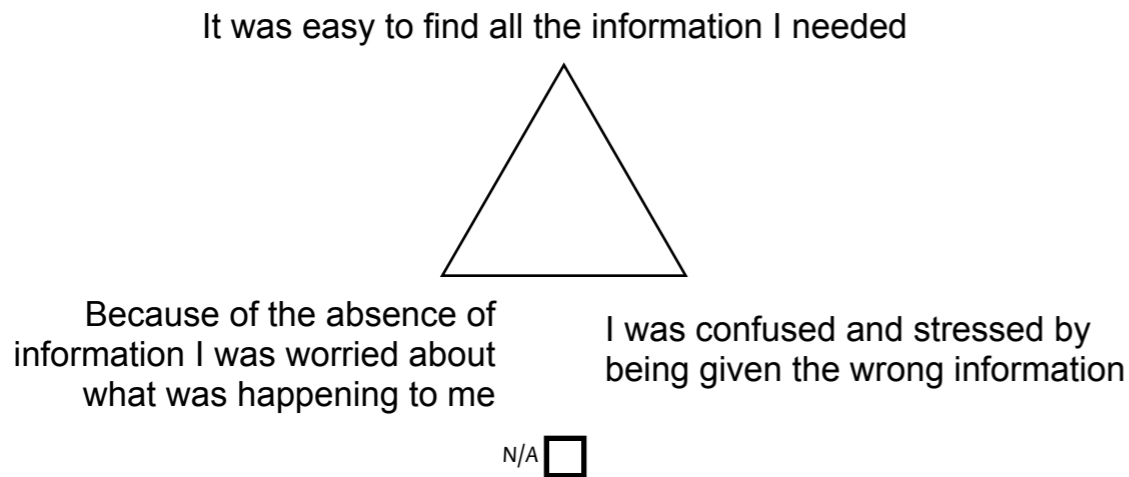
**5. In your story, what was the biggest practical worry for you?**



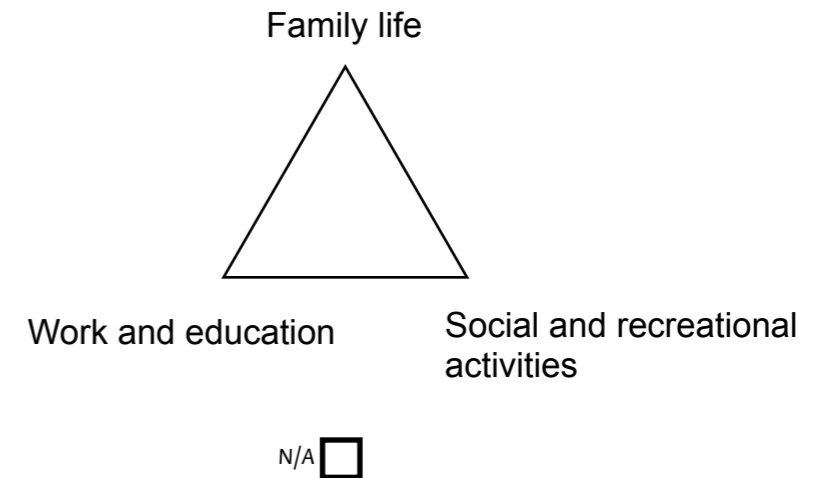
**6. In your story, what level of access did you have to support from all the appropriate services and organisations?**



**7. In your story, how did you find information you needed?**



**8. In your story, what aspect of your life was most disrupted?**



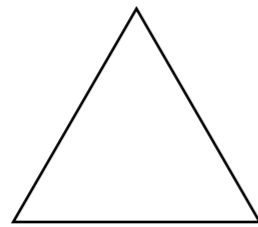


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Please answer the questions by marking the spot on each triangle which best reflects the experience in your story. If any are not applicable, indicate N/A.

**9. In your story, how in control of what was happening did you feel?**

I was able to make the choices I wanted



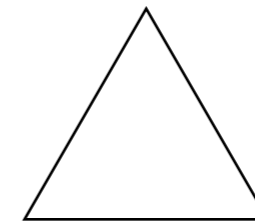
My choices were limited

Control was in someone else's hands

N/A

**10. In your story, who was the most important person(s) for you to talk to about your feelings?**

I dealt with it on my own



My family and friends

Someone else, e.g. GP, social worker, counsellor, support group, nurse

N/A



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## How common is your story?

- Exceptionally rare
- Not at all common
- Somewhat common
- Common
- Commonplace, it's just the way things are around here

## Your age:

- Under 20 years
- 20-29 years
- 30-39 years
- 40-49 years
- 50-59 years
- 60+

## Your gender:

- Male
- Female

## What is your condition?

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## What is your postcode? Just note the first four digits of your postcode (eg BT47 or BT60)

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## Please rate how you found completing this survey:

- Straightforward
- Mixed
- Difficult

Contact details for a range of organisations that provide advice, support and information for people affected by neurological conditions in Northern Ireland are shown on page 3 of this survey. If you have been affected by anything in this survey and would like to talk to someone, Lifeline counsellors are available 24 hours a day, seven days a week to listen and help in confidence on 0800 808 8000. You can also contact the Samaritans by telephone on 08457 90 90 90 or by email at [jo@samaritans.org](mailto:jo@samaritans.org).

