Speak Out For Stroke:
Toolkit for campaigning locally
Toolkit for campaigning locally
The Speak Out for Stroke project was part of the Community Voice Initiative, supported by the Gwent Association for Voluntary Organisations (GAVO) and funded by the Big Lottery from January 2014 to May 2017.

Its aims were to ensure more people affected by stroke had the opportunity to express their opinions about the services they needed, had the ability to influence the services they received and generally felt more included, less isolated and more valued.

The programme was split into two areas: Valley Voices, covering Blaenau Gwent and Caerphilly; and Engage, covering Newport and Monmouthshire.

In this toolkit, we’ve brought together our learnings and experiences from this project to help you to run your own campaigns, and ensure the voice of your stroke community is heard.

“If you don’t say anything and if you don’t push the issue, nothing will happen.”

- Speak out for Stroke Member, Monmouthshire
What is campaigning?

Campaigning, in the most basic terms, is about taking action to achieve changes in a specific policy or law.

The changes can be big or small, local, national or even international. They can affect everyone, or just a small group of people.

Our campaigns aim to create policy or law changes to benefit people affected by stroke.

We believe that campaigning is essential in achieving our goal of a world where there are fewer strokes, people who have a stroke get the treatment and care they need, and people are supported to make their best possible recovery after stroke.

Campaigning can be high profile or involve simple letters and meetings, depending on what is the best tactic and approach to meet your aims.

Who can be a campaigner?

Anyone and everyone can be a campaigner.

All you need is the desire to make a change, and motivation.

Campaigning can be done as a group, either large or small, as well as by just one motivated individual.

Famous campaigns:

- Make Poverty History - Oxfam
- ‘Presumed Consent’ organ donation campaign - Kidney Wales
- The Coalition for Equal Marriage
Why is local campaigning relevant for stroke survivors?

Many of the services stroke survivors tell us are the most important to them are organised and delivered locally.

This could be by the local council, local health board, or services provided by charitable organisations.

Local campaigns can:

• challenge and change decisions to cut services relied upon by stroke survivors and carers
• improve local services that aren’t meeting the needs of stroke survivors, for example, buses which aren’t wheelchair accessible
• ensure local service providers meet their legal requirements, such as providing reasonable adjustments for stroke survivors with disabilities as required under the Equality Act 2010.

Whatever change is required, campaigning enables people to influence their local area, argue for much-needed change and highlight their cause.
How to use this toolkit

We’ve split the campaigning process into five simple steps for you to use as a guide when creating a local campaign. For each of the steps, we’ve listed what you might need to consider, any potential barriers or pitfalls you may encounter (and how to overcome them), and some top tips to make your campaigns as effective as possible.

The five steps are:

1. What is the problem?
2. What is the answer?
3. How are you going to make a change?
4. Carrying out your plans
5. Wrapping up and learning lessons

This toolkit is designed so it doesn’t have to be read all at once, but instead gives you the important information you need at each stage of your campaign.

Campaigns are all about being creative, so you may have ideas or approaches which aren’t covered in this document. However, our campaign team in Wales is always on hand to offer advice, so please email us on info.cymru@stroke.org.uk if you need support at any stage.

When developing a campaign, it is helpful to write down exactly what you are planning to do, to ensure everyone involved is clear on what is happening. To help you with this, we’ve included a handy planning form in this toolkit to enable you to stay on track.
The Caerphilly Speak Out for Stroke Group created a list of four areas they wanted to influence:

- transport
- closure of public toilets
- supermarket access
- leisure activities.

The group particularly wanted supermarkets to be more informed about stroke and more accessible to stroke survivors, so they worked directly with their local Asda and Tesco stores to try and improve the shopping experience for stroke survivors. They designed their own training package with a list of potential improvements and suggestions, and held sessions for Asda and Tesco staff from across south Wales.

The Asda store in Caerphilly has a great relationship with the Speak Out Group. They listened to stroke survivors’ suggestions for improved access in the café, and have invited the group to help oversee the changes.

By being clear with the supermarkets about the problems they wanted to solve, the group were able to have constructive conversations about how they could make supermarkets more accessible and meet their campaign goals.
Step 1: What is the problem?

Your campaign needs to identify exactly what the problem is, in order to suggest ways it can be overcome.

Examples of issues which might affect stroke survivors include:

- long waiting lists for speech and language therapy
- local authorities not conducting carers assessments
- no accessible bus services in some towns or villages
- closure of public toilets
- a lack of available psychological therapies
- cuts to local stroke services
- organisations failing to provide documents in a format usable for someone with aphasia

It also helps to know why the problem is occurring. For example, is it because of budget limitations, not enough staff or perhaps a lack of understanding of the needs of stroke survivors?

An understanding of both what the problem is and why it is occurring will help you to consider how the problem could be solved.

If you are campaigning as a group, make sure everyone agrees on what the problem is, so everyone knows exactly why they are campaigning. The Monmouthshire Speak Out for Stroke Group discussed issues at committee meetings, and then decided which ones they thought were the most important.

Make sure your group decisions are properly recorded, for example in the meeting minutes or on a campaign planning form, such as the one included in this toolkit, so you can be clear about it in future.
Evidence
A campaign needs to be backed up by evidence, so you are able to demonstrate exactly what the problem is and the impact it has on the stroke community.

For example, if you were campaigning about speech and language therapy, you might want to know what the average waiting time is, and how this compares with the average across the health board, Wales or the UK as a whole. Evidence showing why speech and language therapy is important to stroke survivors would also help to make a stronger campaign.

There are lots of evidence sources available, including the examples listed in Appendix 1. You can also request information using the Freedom of Information Act (see Appendix 1 for further details).

Top tips:

• If you’re campaigning as a large group, appointing a Campaign Chair at the beginning could help to ensure things run more smoothly.

• Make sure everything you do is accessible to all. Some stroke survivors may have disabilities and you may need to think about how they can be included. For example, if someone is a wheelchair user and wants to come to a meeting, you may need to book an accessible venue.

• Be clear and specific when identifying the problem. Don’t just decide a service isn’t good enough. What about it isn’t good enough?

• Collect evidence to strengthen your argument.
Step 2: What is the answer?

When campaigning, it is really important to be clear about exactly what you are asking for. It sounds simple, but it’s something that many campaigns struggle with.

If you aren’t clear about what the problem is and what you think the answer is, it is unlikely that the people you are trying to influence will be able to understand your position. Try to be specific and avoid using general terms such as ‘improve’ or ‘better’, which don’t necessarily make it clear exactly how you want services to change.

Example:
**Do** campaign for ‘reduced waiting times for speech and language therapy in the local area’.

**Don’t** campaign for ‘better speech and language therapy in the local area’.

It’s also important to be realistic about the solution. A campaign to replace a poor bus service with a brand new 24/7 monorail service is unlikely to succeed, but changes to the bus timetables might.

“A lot of the disabled trolleys in Tesco were broken, so we wanted them to make sure they had more which worked.

We also wanted: help to get the items we couldn’t reach when shopping; disabled facilities in the ladies changing room; and for Tesco to make the café more accessible.”

Speak Out for Stroke Member, Caerphilly

Top tips:

- Be clear about what you’re asking for so that everyone involved understands the purpose of your campaign.

- Use your evidence to show how the changes you are suggesting would make a positive difference. If you’re using statistics, you could also argue that your solutions might improve the current statistics in future.
Step 3: How are you going to make a change?

It’s easy to get carried away when thinking about campaigns and want to jump straight into the activity. While this approach may sound like more fun, it is less likely to be effective.

A good campaign needs planning. This allows you to think about every step you need to take and time when you need to do it. It can be easy to miss steps and run out of time. For example, if all of the campaign team need to see a leaflet you’ve made, it might take a week to get comments from everyone. Have you factored this in? What about time for translation if you want to do it in Welsh as well?

It is also useful to think about money. Campaigning could have costs attached, such as printing, postage or room rental. Who is going to pay for this? Can you have a similar impact with cheaper options?

Be clear from the start who is responsible for each of the actions you plan to take. If there is a petition planned, who is responsible for writing and printing the sheets? Who is going to collect signatures? Who is bringing clipboards and pens?

Planning enables you to think about the tactics you want to use, and if there are any other people or organisations you want to work with. Planning can also enable you to think about the problems or risks you might encounter during your campaign.

Working with others

One person can change the world, but it’s easier if you have others to help you.

Aside from those who are directly involved in your campaign, it can also be useful to think about who else may be able to support you and ask them to join your campaign. This could include other charities or voluntary organisations, local politicians or community groups.

For example, if you were campaigning for better accessible transport for the local area, you could contact local disability groups, or even parent groups, who might be facing the same problem.

You should also find out if the people you are trying to influence want to be involved. Sometimes they will see the need for change and you’ll be able to achieve more by working with them than you’d be able to if they believed you were criticising them.
If you are working with another individual, group or organisation, make sure everyone agrees on their role in your campaign. They might want to support your campaign but not be actively involved, or they might want to play a full part. Make sure everyone knows and agrees on how they can help.

Ask the people you are trying to influence if they want to be involved in helping to design the answer. A positive working relationship might mean you can achieve more and won’t need a full campaign.

Every type of campaigning tactic will have positives and negatives which will depend on the level of support you have and who you are trying to influence. Try to think about what is going to be most effective for your target audiences.

There are a few other things you can think about when planning:

- Start appropriately – If the person you are trying to influence isn’t aware of the problem they won’t be too happy if the first they hear about it is when people start protesting outside their office. Give people the chance to fix the issue first. You could start with a letter or meeting to highlight the problem, and then plan how you might escalate it further if you feel you aren’t been listened to.

- Build momentum - Some campaign tactics are likely to work better when you have already gained some support for your cause. A big public meeting might not work if you don’t know if anyone will attend, however it could work well if you did a petition first and have the details of those who support your cause (although, please be aware of data protection laws in this instance).

- Be constructive and courteous – The tactics you use will help to set the tone of your campaign. Avoid attacking individual politicians or staff members. Focus on the change you want to achieve and why you want to achieve it.

Tactics

When thinking about how to campaign, there are a huge number of different options available, including letter-writing, petitions, protests and publicity stunts.

Sometimes it can be challenging to work out which are the right options for your campaign, so discussing and planning this as a group can be very useful.

The Caerphilly Speak Out for Stroke Group discussed how they could try and influence supermarkets by speaking to the Gwent Association of Voluntary Organisations to get their ideas.
Planning for problems

Even the best laid plans encounter problems, issues and challenges. However, thinking about what could go wrong before you begin campaigning can help you to prepare and will ensure that you know what to do should any problems arise.

Think about both the risk of something happening and how big the impact would be for your campaign. Something which isn’t likely to occur and wouldn’t be a big problem even if it did probably doesn’t need a great deal of attention. However, if there’s a high likelihood of a problem occurring which would cause big issues, then having a plan for how you would deal with this is a priority.

Top tips:

- Think about the person you are trying to influence and design your campaign around what is likely to have an impact on this person. This may include influencing some of the people who, in turn, have the ability to influence the person you are trying to reach, such as council officers.

The impact of a problem could be financial (it would cost money to fix), time (it could take additional time to fix) or it could be reputational (it would damage people’s image of your campaign).

For example, when producing leaflets or materials to publicise a meeting or event, you might want to think about setting aside some money just in case you need to reprint the information for any reason. Or you might decide to collect the contact details of people who are interested in attending, so if there is an unexpected change in venue or time, you are able to let people know quickly and easily.
Case study: Parking charges in Monmouthshire

The Speak Out for Stroke Group in Monmouthshire had concerns about council proposals to charge blue badge holders for parking in certain areas. They decided to highlight the problem with the council, and ask them not to implement the change.

The group decided to write to the local council, and bring the problem to the attention of other local organisations who could add their voice to the campaign to prevent these charges being implemented.

They researched articles on the issue in local press, and realised that only certain areas deemed ‘affluent’ would be affected. The group agreed this was unfair, as people who have a blue badge have been given one on the basis of their disability, not financial status.

To add weight to their argument, the group sought to find out what costs would be incurred by the local council to change ticket machines to make them accessible to all, and how long it would take to recoup any of the costs. They also asked whether tickets would be transferable across the town if they needed to park in several different places during one visit in order to access the services they needed. These points were outlined in their letter to the council and local press.

The issue was highlighted on the group Facebook page. It was also raised at a local forum held in the Council Chamber, and brought to the attention of local Assembly Members and Councillors. Other organisations sent letters in support of the campaign.

Their campaign was successful and as a result of their work, the proposed charges were not introduced.

The Speak out for Stroke Group’s approach highlights the value of working in partnership with other organisations who might support the same cause, including politicians. It also shows how evidence, such as the cost of the changes, can be used to make a campaign stronger and show why your arguments are valid.
Step 4: Carrying out your plans

After plenty of planning and preparation it is always exciting to start carrying out your plans. By this stage you should know what you’re doing and be ready for what lies ahead. However, there are still a few things to remember.

• **It is useful to keep people involved and informed throughout your campaign.** Some campaigns are quick, but others can take a long time. Keeping a record of everyone who has supported you means you can ask them for help again later on if you need it. Keeping them up to date with what you’re doing makes everyone feel involved and part of the cause. Social media can be a great tool for doing this as it is both cheap and easy to use.

• **Try and involve the people you are trying to influence.** You can achieve more by working with people, rather than being seen to be critical of them.

• **Don’t be disappointed if you don’t succeed straight away.** Campaigns often need momentum and continued pressure. Having more than one stage to a campaign can help achieve this.

• **Regularly review your plans.** You’ll need to respond to the people you’re trying to influence and might need to change your initial ideas.

• **Not everyone is going to agree with you.** You may encounter people who either don’t want to support you or are hostile for many different reasons. Don’t take this personally and always deal with people who disagree in a polite and courteous way.

• **But be aware of the General Data Protection Regulation!** If you are taking people’s personal information, make sure you have their informed consent and only use it in the way you said you would. For more information, please visit the Information Commissioner’s Office website - [https://ico.org.uk](https://ico.org.uk).

For information about the Stroke Association’s privacy policy, please visit [stroke.org.uk/privacy](http://stroke.org.uk/privacy).
Step 5: Wrapping up and learning lessons

Hopefully, your campaign ends in success and you achieve the changes you set out to achieve. If so, well done!

Unfortunately, not every campaign will be successful and sometimes, despite your best efforts, you might have to admit defeat. It can be a difficult decision to make, but if you think no amount of effort is going to achieve your goal, then there is nothing wrong with calling it a day.

Whether your campaign is successful or not, it is important to make sure you thank everyone involved for their work and support. You can also try to capture anything you’ve learnt from your campaign to share with others.

If you’ve got a really engaged group, you could also see if there is anything else people want to campaign on and keep the group going.

Also, whatever happens, be proud of yourself for the hard work you’ve put in and for making sure the needs of stroke survivors have been heard and considered!

“It all looks doom and gloom and then you challenge the official position and they back away.”

Speak Out for Stroke Member, Monmouthshire
Getting more involved in campaigning

If you want to get more involved with the Stroke Association’s campaigns on national issues affecting stroke survivors and carers, there are a number of ways you can do this:

Join the Campaigns Network via our website: stroke.org.uk/webform/join-campaigns-network

The Campaigns Network is a monthly email newsletter, that provides information, updates and actions you can take to help us to achieve changes that will benefit stroke survivors around the country.

We also provide training and support for people who are interested in campaigning. To find out more please email: campaigns@stroke.org.uk

Campaigning as part of the Stroke Association

If you use our services or attend one of our groups, you may wish to campaign as part of this group.

Groups are welcome to campaign as part of the Stroke Association, but have to ensure they do so in line with our own policies and values.

Any campaign undertaken as a Stroke Association group or service must be related to stroke, including the rights and recovery of stroke survivors. Your campaign must be neutral of any political party, in line with our agreed policies and not involve any ‘direct action’ (campaigning activity which could get you arrested).

We have developed a ‘Campaigners Agreement’ which details exactly what the rules are when campaigning with the Stroke Association. It also details any rules about campaigning outside of the Stroke Association on areas relevant to our work.

Anyone campaigning as part of the Stroke Association must sign the Campaigners Agreement.

Please email campaigns@stroke.org for more information and to request a copy of the agreement.
Further information

Change.org

Change.org is a social enterprise which hosts electronic petitions and allows petitioners to easily share their petition and gain signatures, as well as engage with the people they are trying to influence.

Website: change.org

Disability Wales

Disability Wales is a membership organisation for disability groups throughout Wales. They champion the rights, equality and independence of all disabled people and campaign at all levels.

Website: disabilitywales.org
Tel: 029 2088 7325
Email: info@disabilitywales.org

National Assembly for Wales – Petitions Committee

The National Assembly’s Petition Committee is a great way to highlight your cause to Assembly Members, provided it is regarding an area which is devolved to Wales.

Website: assembly.wales/en/ghetehome
Tel: 0300 200 6565
Email: seneddpetitions@assembly.wales

Welsh Council for Voluntary Action

The WCVA support and work with the third sector in Wales. They provide advice and training to charities and third sector groups, including information on campaigning.

Website: wcva.org.uk
Tel: 0800 2888 329
Email: help@wcva.org.uk
Appendix 1: Evidence Sources

InfoBase Cymru

InfoBase Cymru is a Data Unit website bringing together data about Wales from local authority to local level – covering a wide range of health and social care data.
Website: infobasecymru.net

Office of National Statistics

The Office of National Statistics is the largest independent producer of official statistics and the recognised national statistical institute of the UK.
Website: ons.gov.uk

Stats Wales

StatsWales is a free-to-use service which allows you to view, manipulate, create and download tables from Welsh data.
Website: statswales.gov.wales

Sentinel Stroke National Audit Programme (SSNAP)

SSNAP gathers data on stroke services from stroke units and details statistics on performance and grading each service area in each hospital quarterly.
Website: strokeaudit.org/results/Clinical-audit/National-Results.aspx

Stroke Association – State of the Nation 2018

The Stroke Association report ‘State of the Nation’ looks at many different statistics and information around stroke, including statistics for Wales and the rest of the UK.
Website: stroke.org.uk/resources/state-nation-stroke-statistics

Welsh Government

The Welsh Government releases their own statistics on a range of subjects relevant to devolved areas.
Website: gov.wales/statistics-and-research

Using the Freedom of Information Act

The Information Commissioner has produced guidance on how to write a Freedom of Information Request, when to use them and how they work.
Website: ico.org.uk/for-the-public/official-information/
## Appendix 2: Campaign planning form

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<th>Campaign planning form</th>
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<td>Campaign name</td>
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<td>Campaign goal</td>
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<td>Who is involved in the campaign?</td>
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<td>Does the campaign have a Chair or Head? If yes – who?</td>
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<td>Does the campaign have anyone else with a particular role? If yes – who?</td>
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<td>What area does the campaign cover?</td>
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<td>What is the current problem the campaign is aiming to solve?</td>
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<td>What is the solution to this problem which the campaign aims to achieve?</td>
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<td>What evidence do you have to show why there is a problem and why your answer is the solution?</td>
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<td>Who do you need to influence to solve the problem?</td>
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<td>Are there any other organisations or individuals you should involve with or talk to about the campaign?</td>
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## Campaign Actions – Be as detailed as you can!

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<th>Action and influencing target</th>
<th>By when?</th>
<th>Who will do this?</th>
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## Risks

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<th>What risks are there to the campaign?</th>
<th>How likely is it this problem could happen?</th>
<th>What would the impact be?</th>
<th>What steps can you take to prevent it occurring or minimise impact?</th>
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We are the Stroke Association

We believe in life after stroke. That’s why we support stroke survivors to make the best recovery they can. It’s why we campaign for better stroke care. And it’s why we fund research to develop new treatments and ways of preventing stroke.

We’re here for you. Together we can conquer stroke. If you’d like to know more please get in touch.

Stroke Helpline: 0303 3033 100
Website: stroke.org.uk
Email: info@stroke.org.uk
From a textphone: 18001 0303 3033 100

We are a charity and we rely on your support to change the lives of people affected by stroke and reduce the number of people who are struck down by this devastating condition.

Please help us to make a difference today.

facebook.com/StrokeAssociationWales
@StrokeWales

Together we can conquer stroke