

University of Essex

A gap in service provision after stroke and journeys of survivors

tending specialist
STROKE
services



A report on collaborative work by local stroke survivors, carers and specialist services, co-ordinated by Tendring Specialist Stroke Services (TSSS) and the School of Health and Social Care, University of Essex.

This report has been compiled by the Stroke Research Group.

The members of the group are:

Bruce, Darragh, Lorna, Marian, Moira, Nikki, Wendy and Will

We would like to thank everyone involved for their commitment to the review, sharing resources and personal experiences of stroke.

We would particularly like to thank TSSS for funding the refreshments for meetings and the Bowling Green for hosting our meetings.

Please share this report. Further copies of this report are available from Tendring Specialist Stroke Service
www.tendringstroke.org.uk/

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Flower craft by Moira Prentice

Photographs by Nikki Williamson

Preface

My whole-hearted congratulations go out to the team on this informative and inspiring project.

Bruce, Darragh, Lorna, Marian, Moira, Nikki, Wendy and Will have made visible the challenges faced by stroke survivors under 65. They have also demonstrated how shared knowledge and experience can provide the basis of effective action to help younger stroke survivors re-engage in valued activities and roles.

Their report provides a message of understanding for younger stroke survivors. Their work offers a model for groups around the world looking to promote positive changes in stroke care in the community.

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Brief summary

We wanted to find out more about life after a stroke, for people who are aged under 65. This was part of a bigger project to explore how local services could be more helpful. Previously, there had been a survey of local people in Tendring who had a stroke and their carers. Now we wanted to find out what people were writing. We called it a “scoping review”: to scope out what was being said, reviewing what was being written about current research.

A group of 8 people, including stroke survivors and their carers, had 10 meetings to do the review, guided by an occupational therapist from the University of Essex. From January 2017, we met at a local pub which was very accessible and provided us with hot drinks, funded by Tendring Specialist Stroke Services (TSSS).

By November 2017, we had findings to share, and a list of local resources which group members wanted to share with others. This is available via TSSS website (see p.18).

We found out that everyone is different but being younger when you have a stroke makes things very complicated, especially with work. Getting the timing right is very important. Bringing people together makes it easier to find out about what can help. Services must work together: we created a map to understand how they can do this. The next step is to share our findings with local services to explore where to start, to fill the gap.



Why this work was needed



Every year stroke affects about 250,000 people under the age of 65 years, whose lives are changed for many months and even years. There is limited help from local services and communities for specific challenges such as being a parent, going back to work and money.

This work took place in Tendring, a popular place to retire to on the Essex coast. Many services focus on older people, especially after people have been discharged from hospital. Tendring Specialist Stroke Services (TSSS) were keen to find out more about what they could offer. Since 2014, they've worked with occupational therapists from the University of Essex. People were surveyed about their needs after a stroke and three occupational therapy students have had work placements at the main centre (see photos above). Ideas have been shared at an international conference. This report shares the next stage in developing our knowledge about the problem.



What we aimed to do

- Find out more about what helps people who have had a stroke before the age of 65, from published research
- Work together to review what has been written by researchers and other experts
- Share our knowledge and experience about surviving life after a stroke and local resources to help



Who was in the group

There were 8 people in the group and everyone in the group had experience of stroke. Some people had had a stroke themselves, and others cared for family members. Our group also included an occupational therapist from the University of Essex, who coordinated the project with a member of staff from Tendring Specialist Stroke Services. Another occupational therapist, from local NHS community services, was involved.

Additional people attended less often, for example the people involved in the bigger project, a senior occupational therapist from the university and the chair of Tendring Stroke Support Services.



Working together

We started our work together by sharing our experiences, to get to know each other and find what worked for us. We called our work a “scoping review”. This means we were scoping out what had been written about research and reviewing it. We focused on research because we wanted to know what other people had been doing and whether it helped.

This meant we read research papers, talked about them together and discussed whether we thought they were relevant. We also discussed whether there were any good ideas or things to be learned, which could apply locally. People shared their thoughts about the papers and their own experiences, reviewing how helpful the research was, or not.

We had to agree where to start and how we were going to stay focused. Our review covered the following topics:

- **General needs of people under 65 who had a stroke**
- **Long term needs**
- **Living in the community**

For each meeting, we read research papers which had been found by the occupational therapist from the university, based on what we wanted to know more about. Other publications were shared too, to help us understand as much as we could.



Overview of what we found

We found that we had knowledge we could share with each other as well as learning from the published research papers. To bring our ideas together, we used a mapping approach.

Resource list

We shared knowledge about resources, from which we created a list which includes information about websites, specialist guides and local organisations. This list can be obtained using the contact details on page 18.

Learning from the research papers

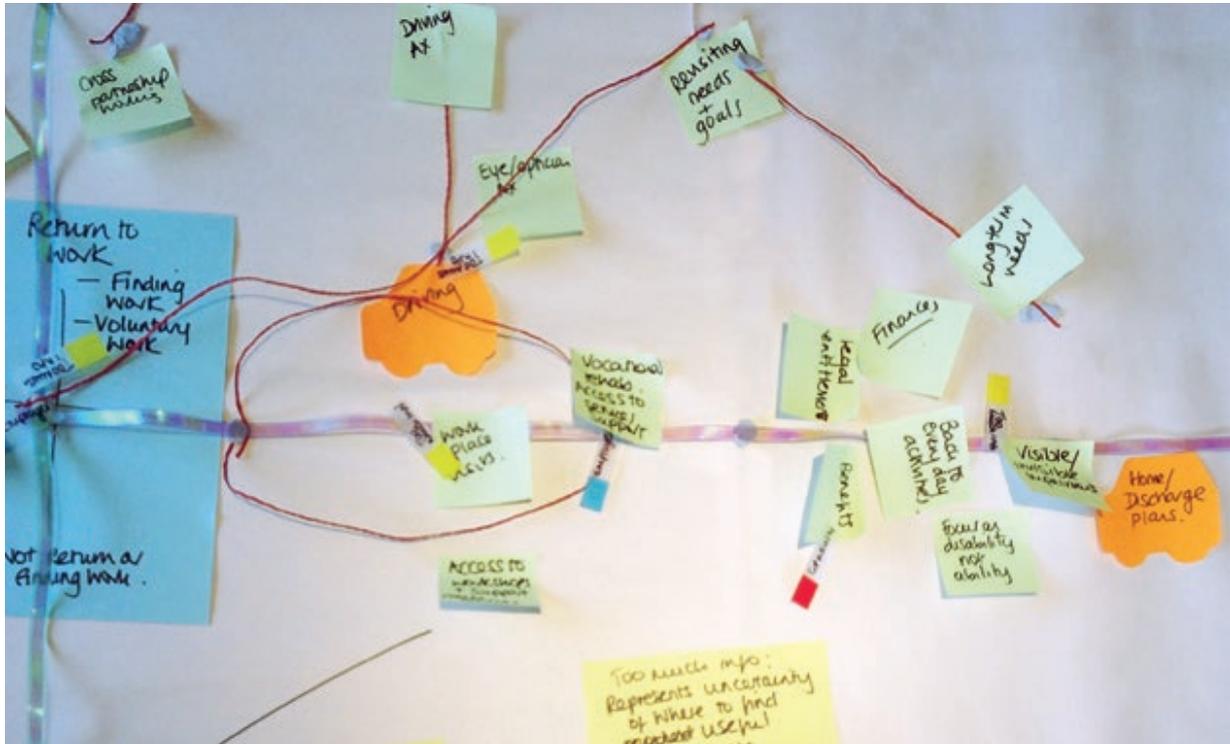
We read 10 different papers. With careful thought and discussion, we found there were two common themes, which are presented in more detail from pages 13-14.

- **Everyone is different**
- **Finding the right time**

This approach was very similar to a literature review, which researchers do at the beginning of a research project. They search for papers, exploring and analysing what is already known about a topic. Our approach was very similar, but the university occupational therapist found most of the papers. Our discussions were very thorough because of our experiences of stroke. People who have direct experience are not often involved in this stage of research.



Mapping the stroke journey in Tendring



One group member was experienced in business mapping and inspired us to create a map of the journeys which people travel when they have a stroke.

We started with hospital admission, travelling through early support discharge or community rehabilitation services to ongoing community support and needs. This included: driving, return to work, emotional support, and being ready to participate and engage back in the home environment.

What we had learned, from the research papers and from each other, formed the content of the map.



Everyone is different

The first common theme we found from the research papers was that everyone's experience is different. However, there were some important findings which affect what happens to individuals, which professionals, community services and employers should be aware of:

Visible and invisible impairments. If a person's problem can be seen, then it is easier to get help. For example, for a person using a wheelchair, an employer is more likely to make "reasonable adjustments" which are legally required. When impairments cannot be seen (they are 'hidden' or 'invisible'), it is more difficult to get help from anyone. This means problems like fatigue, word finding difficulties and thinking things through (cognition) get overlooked or ignored.

Return to work is important but there is a lack of support from employers and specialist services (vocational rehabilitation). Invisible impairments are not understood but also people do not work together, known as cross partnership working. There could be partnerships with stroke survivors, carers, professionals, employers, employment and stroke specific support agencies/ organisations.

Limited research which tends to focus on short term problems like Transient Ischemic Accidents (TIA) and/or the impact of mild stroke. It is not always clear how levels of stroke are identified (mild, moderate, severe).



Finding the right time

In addition to the research papers, we discussed the national guidelines for best practice in the UK, created by the government (NICE) and the Royal College of Physicians. These guidelines say that providing information and advice about work and community participation is very important.

But local services vary in how much they do this. This is because follow up after a stroke is limited to between 6 and 12 months, information is not always shared at the right time for people and not everyone has access to specialist stroke support. Not all information is helpful for people of working age, for example:

Knowing what to expect. There is a lack of knowledge and support from employers and services about returning to work after a stroke, as recovery times vary. Ability to work is affected by personal and family expectations. There are financial implications to not working, including having to respond to government expectations about being in work with a disability.

Challenges with employers if you've had a moderate or severe stroke. Not enough is known, as the research focuses on mild stroke and it is difficult to tell if people will continue to improve.

How to get support to return to work. It is difficult to find out how to access services which could help, if there are any. These services can be provided by private organisations and



charities, which may have a lack of specialist staff to deliver appropriate support and guidance.

Cross partnership working is essential so that support is relevant and at the right time, including understanding rights to work. This can include role change, unpaid voluntary work or retraining. The research we found did not indicate that cross partnership working was happening consistently or how effective it was.

Our experience

We gained so much from working together.

We realised how much knowledge we shared, from our experiences as stroke survivors and carers with our expertise of stroke, using services, professional knowledge and other identities including: wheelchair user, academic, web designer, ex-employees, local volunteer and members of local voluntary support groups.

We also brought our professional expertise from working in local services with many people surviving a stroke.

We valued sharing resources, discussing benefits and challenges on topics such as; accessibility, transport, work, service provision and being ready for participation.

Working together highlighted the value of sharing knowledge and resources with the wider community. See the Next Steps on page 17 for our plans.



Learning from this scoping review

The research findings inspired us to discuss many things in detail. We believe it is very important to understand what the challenges of surviving a stroke feels like: for example; how a stroke has long term effects on thinking, energy levels, vision and speech.

Sharing experiences is important; to know what resources are helpful and currently available.

Reducing the chaos in the early days would stop people feeling overwhelmed in hospital. Life changes so much after a stroke and adjusting can be helped by a carefully planned person-centred approach to care, support and information.

People providing services must recognise when people are ready. Not everybody is ready for information at the same time. Many people need information after discharge.

Working together gives people a better chance of getting back to work. This means everyone involved: health, social care, voluntary organisations, support groups, job centre plus, benefits agencies and local employers.

National practice guidance and research evidence can be used to justify new developments, to fill the gap in community services for working age stroke survivors.



More research could be done to understand our experiences, how services could be provided at the right time, and how information and resources could be shared.

Our next steps

- 1.** Share our findings, including an event with people who lead local services.
- 2.** Make our list of resources accessible
- 3.** Explore whether mapping would help bring different services together in Tendring.
- 4.** Do more research:
 - a.** Explore long term personal experiences of stroke (MSc project completed)
 - b.** Explore opportunities for accessing community support/resources during work time e.g. attending exercise groups, to know rights in the work place including flexible working patterns
 - c.** Investigate the prevalence of stroke in working age adults and longer-term needs in Tendring



Useful contacts

Tendring Specialist Stroke Service	www.tendringstroke.org.uk Phone: 01255 815 905 Email: info@tendringstroke.org.uk Address: 85 Frinton Road, Holland-on-Sea, Essex, CO15 5UH
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ACE- Early Supported Discharge Team	www.acecic.co.uk
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Stroke Association	Colchester Stroke Recovery Service www.stroke.org.uk/finding-support/colchester-stroke-recovery-service
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Different Strokes	www.differentstrokes.co.uk Colchester exercise group Phone: 01206 585 043 colchester@differentstrokes.co.uk
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Colne Stroke Group	www.colnestrokegroup.org.uk
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Success after stroke	www.successafterstroke.org.uk
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East Anglian Driveability	www.eastangliandrivability.org.uk
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Headway Essex	www.headwayessex.org.uk
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For the full resource list see TSSS Website:

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



List of reviewed sources

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13. Imrie R (2004) Demystifying disability: a review of the International Classification of Functioning, Disability and Health *Sociology of Health & Illness* 26(3):287-305





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I luckily managed to keep my job working from home after my stroke, but my life and health would have been made so much better given independent advice on flexible hours, so I could have undertaken group exercise. Just the knowledge that it could be there would have made a massive difference.

Stroke survivor

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All group members contributed to the content and development of this report