

A loved one has had a stroke...

A guide for family and
friends to help you
support both the stroke
survivor and their carer

Every Stroke is a different journey



Boroondara Stroke
Support Group

Letter from the President and the Executive Committee

On behalf of the Boroondara Stroke Support Group Inc. and our Executive Committee of Management, I would like to offer my sincere, personal and heartfelt thanks to you for reading this booklet. Sadly, it possibly means that someone close to you has had a stroke. However, we are very grateful that you are demonstrating your concern by seeking ways to help others in need of your support.

This booklet has been written with contributions from stroke survivors and carer members of the BSSG Inc. after detailed research over a long period of time and we sincerely thank them for their invaluable, thoughtful and meaningful input.

We do hope that this booklet will assist you to be there for your family or friends.

However, please do not hesitate to call us on (03) 8529 5307 or go to our website www.bssg.org.au for further support and information.

Yours sincerely and gratefully,



Vivienne Harkness OAM

President

Boroondara Stroke Support Group Inc.

Introduction

We all need the mental and physical support of family and friends throughout stressful periods of our lives.

Sometimes families or friends of stroke survivors can find the condition too confronting, and may even drift away. They may find it difficult to accept how their loved one has changed, not realising that the person is 'still there' and longing for some normality in their life and their relationships.

This document has been prepared from the experiences of stroke survivors and carers who have come to the Boroondara Stroke Support Group Inc. (BSSG) for assistance and support.



Behaviours to expect from a stroke survivor

It is difficult to generalise about strokes because strokes are caused by damage to the brain and the brain is enormously complex.

The brain controls every aspect of the body's functions, so the result of a stroke depends precisely on where in this large, complicated organ the damage occurs. It may result in mobility or dexterity issues such as difficulty with walking or using an arm. Problems with speech, thinking, reasoning or understanding are also common.

These kinds of problems will typically take a lengthy time to improve, so some form of lasting disability may be the result. The prospect of a lengthy recovery and an unknown future, are likely to result in anxiety and depression.

There are many symptoms following a stroke that may cause significant distress, confusion and frustration for stroke survivors, including:

- brain fog
- physical limitations
- problems with speech
- mood swings
- anger
- self centredness
- lack of appreciation that others are offering care and consideration.

Please be patient and try and remember that these emotions are often outside the person's control. Inside, they are still the person you knew and still care about.

Another common problem experienced through a stroke is fatigue, which can be debilitating. So try not to think of the stroke survivor as being anti-social or uncooperative if they cannot keep up the same pace as before, or that they are being unmotivated and lazy if they struggle with rehabilitation and other situations. Also keep in mind that carers can suffer from fatigue and need understanding and support.

Helping a friend or family member

Learn about strokes

As most people know little about strokes until it enters their lives, it can be beneficial to do some research into the condition. This will enable you to assist the stroke survivor more effectively.

Good sources of information and knowledge about stroke include brochures, books and the internet. Useful information can be found with the Stroke Foundation and Carers Victoria. BSSG also has brochures and reference books in our library.

BSSG differs from these organisations in that it provides activities for stroke survivors and carers living in and around Boroondara. Our activities aim to provide social interaction and fun as well as some practical skills development.

How to offer emotional and practical help to stroke survivors

- Remember each stroke journey is different, so do not assume you know what the stroke survivor is going through, even if you know a bit about strokes. They are an expert on what is going on with their situation.
- Listening is of paramount importance, and it is important to be a willing and sympathetic listener when they are able and/or wanting to talk.
- With a relative, be prepared to discuss family matters that they deserve and need to know about. Refrain from burdening them with your worries if possible.
- Ensure they are part of any discussion about their future.
- Be positive about the future to them. Remind them that things will get better than this.
- Gently urge patience if they are frustrated with their slow progress. Remind them they are in a marathon, not a sprint.

- Ask them “How are you feeling?” Do NOT say “I can understand how you feel” – because you don’t, unless you have had a stroke yourself. Better to say “I can’t imagine how you are feeling, would you like to tell me about it?” and then listen.
- Remember that contact with stroke survivors is essential for their well being.
- Offer practical help if possible, such as shopping, transport to medical/therapy appointments, housework, personal care, taking them on outings of particular interest to them. Encourage them to become involved with a local stroke support group.
- Take an interest in their rehabilitation. Encourage them to talk about it and maybe ask if you can sit in on a session or two.
- Encourage them to think about the future and what they might be able to do, rather than dwell on what they used to be able to do; for example:
 - > Driving – if it looks like being a possibility for them
 - > Returning to work – if it looks like being a possibility for them
 - > Engaging in community activities
 - > Engaging in exercise.
- Be aware, especially if they are early in their recovery journey, that they may find thinking about the future too confronting. Encourage thinking in the short-term and taking things one-day-at-a time.
- Be aware a stroke survivor may feel awkward in a social situation; make sure they are included if possible and not isolated.
- Their self-esteem and confidence will have taken a terrible beating; try to boost them any way you can.
- When conversing with a stroke survivor with speech difficulties, try to frame questions that elicit a “Yes” or “No” or other short responses. Or, encourage them to use a nodding or shaking head/hand gesture.

What doesn’t help: things to avoid

- Avoid the temptation to offer solutions, to go into problem solving mode, when a stroke survivor unburdens themselves to you. Often, they just want to vent, want someone to listen and be sympathetic. To have a non-stroke sufferer, who really cannot appreciate what they are going through, offering what seem to them glib solutions can be irritating and counter productive.
- Avoid trying to offer words of consolation. A stroke is an extremely traumatic experience and no words will change that.
- Don’t shout. The stroke survivor is not deaf. Talk naturally and slowly.
- Avoid loud noise and flickering lights – eg. a radio, a TV, or a crowded room. Due to possible increased sensitivity, these can be stressful for your stroke survivor.
- Beware of offering anecdotes of stroke success stories, of people you know who have had a stroke and 6 months later are running marathons. It’s not a competition.
- Avoid saying “be careful” to stroke survivors with mobility/dexterity weakness. While doubtless well meant, it can be taken as implying they are not careful, and showing you lack faith in them. You should realise no one is more careful than such people; they have to be. If they stumble or drop something it is not because they are careless.
- Beware of being overprotective and discouraging a survivor to push themselves, especially those with mobility/balance issues. Be encouraging and supportive and reinforce strategies suggested by their Allied Health Team (Physiotherapists and Occupational Therapists).

And finally

Don't think the above means stroke survivors are thin-skinned creatures to be handled with kid gloves; that you have to "walk on egg shells" around them.

They may be physically weak, but they are tougher than they look or seem. They have already been through an extremely traumatic experience and survived. They just need people to try to empathise with the confronting world they are now forced to inhabit.

It all comes down to listening a lot, and maybe talking a little less.



Care and Concern for Carers

Behind almost every stroke survivor is also a loving, caring carer.

A stroke can shatter and change the lives of many marriages, partnerships, families and friendships, in a matter of minutes.

The world for all concerned is turned upside down and can cause uncertainty and fear, which can lead to feelings of anxiety and depression.

Carers Also Need Support

As a friend or family member you can provide invaluable support for carers in some of the following ways:

- Call them as often as appropriate and encourage them to express their feelings - and then listen.
- Ask how he/she is - not just about the progress of their stroke survivor.
- Invite the carer out for coffee or lunch, being mindful that they often do not have much free time.
- Offer to visit and care for the stroke survivor at their home or offer to engage him/her in an external activity to enable the carer to have a break - eg - take him/her for a coffee, a walk, a scenic drive when physically possible.
- Offer assistance - shopping, transport, walking their dog etc.
- Offer to cook meals and special treats for them to enjoy.
- Do not be judgemental - encourage them to openly express their feelings of possible fear, frustration and loss of their own personal quality of life.

- Be aware that previously the everyday tasks of running their lives and households had been a shared role. Depending on the impact of the stroke, these roles may now need to be done, mainly by one person - the carer - eg. cooking, cleaning, gardening, driving, social activities, parenting, grand parenting, maintaining accounts, working and many other day to day living tasks. Listen to them, encourage them to talk about these concerns and if they are being able to cope with these extra loads. If practical, offer to help.
- Remember too that the stroke itself will have added a considerable extra need to the normal workload for the carer, depending on the type and severity of the stroke.

Above all be a patient concerned listener - carers can often be experiencing severe loneliness - by just giving them some of your time will be invaluable for their wellbeing and in turn help the stroke survivor as well.



This document has been prepared by members of the Boroondara Stroke Support Group Inc (BSSG). Special thanks to Vivienne Harkness (former carer, and current President of the BSSG), Peter Hocking (stroke survivor) and our late Liz Berryman (carer).

BSSG provides a range of activities for stroke survivors and carers living in and around Boroondara. These activities, which are listed and updated monthly on our website www.bssg.org.au, provide social interaction and fun as well as some practical skills development for stroke survivors and carers.

The BSSG is supported by a part-time administrator and a team of volunteers.

The BSSG receives no ongoing funding. It is currently able to fund itself through local grants and the generosity of its members and community.

Any donation you could give now or later to the BSSG would be very much appreciated, and would help contribute to our mission of supporting stroke survivors and their carers in their time of need. As BSSG has tax deductibility status (DGR), any donation over \$2 you would give us is tax deductible.

For further information about how we may help you in your journey as a carer, friend or family member of a stroke survivor, please contact us at:

Boroondara Stroke Support Group Inc.

533 High Street, Kew Vic 3101

PO Box 2260, Hawthorn Vic 3122

Open Mondays to Thursdays (10am – 3pm)

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