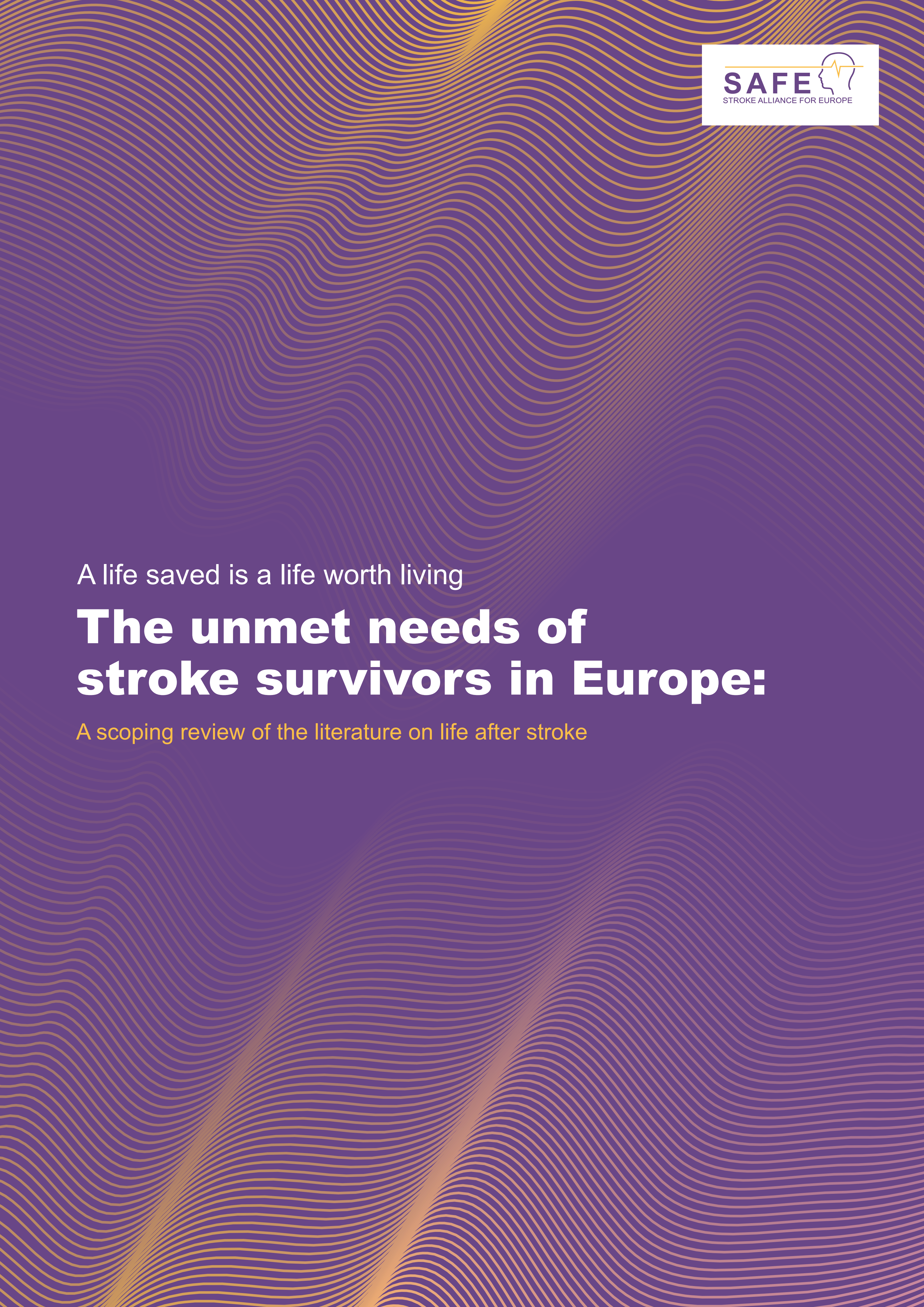

SAFE
STROKE ALLIANCE FOR EUROPE

A life saved is a life worth living

The unmet needs of stroke survivors in Europe:

A scoping review of the literature on life after stroke

The Stroke Alliance for Europe

Involvement of stroke survivors and other stakeholders in the review

The review process and report were designed in collaboration with a working group comprising members of the SAFE governance board, including two stroke survivors.

The group discussed the approach and drafts of the report during regular online meetings. One of the King's College London review team is a stroke survivor.

The authors would like to thank these stakeholders, and also thank Fara Hamidi, Research Assistant at King's College London, for contributing to an earlier draft of this report.

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The School of Life Course & Population Sciences is one of six Schools that make up the Faculty of Life Sciences & Medicine at King's College London. The School unites over 400 experts in women and children's health, nutritional sciences, population health and the molecular genetics of human disease. Our research links the causes of common health problems to life's landmark stages, treating life, disease and healthcare as a continuum. For more information on The School of Life Course & Population Sciences,, please visit **www.kcl.ac.uk/slcps**

The Stroke Alliance for Europe (SAFE) a non-profit-making organisation formed in 2004 in Brussels, Belgium. It is the voice of stroke patients in Europe, representing a range of stroke support organisations from more than 30 European countries. SAFE's vision is a better future - a Europe where preventable stroke is eliminated, death and disability minimised, and every person affected by stroke lives their best life possible. For more information about SAFE, please visit **www.safestroke.eu**

Editorial advisor: Joe Korner

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1. Preface

This report is the third in a series commissioned by SAFE providing a picture of stroke in Europe. The first two, The Burden of Stroke in Europe and At What Cost, The Economic Impact of Stroke in Europe aimed to present definitive figures on the numbers of people having a stroke and living with life after stroke. Based on the latest research, they provided projections for the future impact of stroke – on individuals, on communities and health systems and on economies.

This report, ‘A life saved is a life worth living’, does not deal with numbers, or projections. Instead, it seeks to map what we know about the various needs that stroke survivors have in the long-term and the extent to which those needs are being met. This is the shorter version of the report. The longer version includes more details on what we found and contains definitions of need, our methodology and all of the references. **More details**

Advances in stroke care over the last two decades have transformed our expectations. We have seen emergency and acute care, if organised according to guidelines, save lives and reduce disability. We have seen a growing acknowledgement that what happens to stroke survivors after they leave hospital is vitally important, however, they consistently report feeling abandoned once they leave hospital. Our knowledge of the needs of stroke survivors and what interventions might help to meet those needs remains patchy and often only anecdotal. This paucity of evidence is even worse when we consider the needs of stroke survivors in the longer term and how they might change over time.

The great advances in stroke medicine should be matched by a concerted effort to make sure that stroke survivors can live their best possible life after their stroke. We hope that by bringing together as much of what we know about the needs and unmet needs of stroke survivors, we might help to make sure that stroke survivors and their carers can make their lives as good as possible.

The literature search we conducted was as wide as possible and included surveys and qualitative research which can sometimes be overlooked. As this report shows, however, the evidence remains predominantly concerned about the medical issues stroke survivors face in the long-term, rather than the social needs of stroke survivors. To some extent only a proportion of the very important issues that impact on the wellbeing of stroke survivors are being researched and understood, let alone addressed.

There is a paucity of evidence about the stigma and prejudice that stroke survivors face; very little about the difficulties stoke survivors face in accessing community and social life; or the financial impact of stroke on individuals and families, for example. There is very little research into the changes in health, wellbeing and disability that stroke survivors can experience many years following their stroke.

In our search we found examples where a particular issue was addressed in just one question in one survey or piece of research, demonstrating that there are many needs faced by stroke survivors that are not adequately researched. Across Europe many stroke survivors are discharged from medical care into the community without follow-up or specialised stroke support, where stroke survivors, their families and loved ones have to quickly gain an understanding of their needs and the practicalities of life after stroke. The Stroke Action Plan for Europe has strong recommendations about life after stroke. More research is required. But also, systematic research into the non-medical needs of stroke survivors is badly needed if we truly aspire to a world in which stroke survivors can live as good a life as possible.

The key themes that emerge are:

- There is too little research into the long-term needs of stroke survivors and their carers, exacerbated by a lack of common ways of understanding, measuring and meeting needs. This means that stroke survivors are being left with a range of often very debilitating unmet needs.
- There is a severe lack of consistent information, preparation and support for stroke survivors and their carers to enable them to understand and best tackle their long-term needs over time.
- The provision of community-based rehabilitation therapies and support is falling far short of people’s needs.
- Secondary prevention advice and support is failing to help people reduce their risk of having another stroke.
- Many chronic symptoms such as memory and concentration problems or fatigue and mental health are not well understood, poorly researched and lacking in interventions that work.
- Carers’ needs are under-researched and often ignored in service provision.

Therefore, our recommendations are:

- Governments and research bodies should provide funding to investigate the medium and long-term needs of stroke survivors and the improvements in service provision to meet those needs.
- Health and social care systems should be designed to provide high-quality information and support for stroke survivors and their carers that is easily accessible over the long-term.
- All stroke survivors should be followed up, at least annually, by a stroke specialist to have their physical, mental and societal needs assessed and to be referred to relevant services.
- National and local health and social care systems must improve access to rehabilitation therapies for stroke survivors for as long as they continue to show benefit.
- National and local health and social care systems must improve the provision of and access to secondary prevention services and support.
- More specialist support is needed post stroke to help stroke survivors cope with ongoing issues such as chronic fatigue, concentration problems and mental health support.
- People supporting and caring for stroke survivors should have timely access to information and support, including meeting their needs to self-care.
- Stroke specialists and health planners should develop a European-wide model of care or set of principles (with an agreed definition of un-met need) to guide the provision of services to meet the long-term needs of stroke survivors.

2. Introduction

Everyone's stroke is different. In the emergency and acute setting there are clear evidence-based guidelines about the best interventions to reduce mortality from stroke and maximise a person's recovery. There are less detailed recommendations about what support should be given after someone is discharged from hospital though some are crystal clear – for example, the need for rehabilitation therapies to continue after hospital, or the need for follow up review meetings. And while real-time stroke audits can monitor good (or bad) practice in the hospital setting, this is much harder to do in community settings.

There is plenty of evidence to back up the guidelines for the acute phase of stroke, but much less about best practice afterwards – especially as gold standard research methods (for example, double-blinded, randomised controlled trials) are much harder to use in community settings. As the evidence base gets thinner, it is also the case that lives are much more complicated once someone gets home from hospital. It is much harder to generalise about what people need and what interventions might be useful.

The aim should always be that stroke survivors should be able to live as good a life as possible, but what that looks like is often opaque. The shock of stroke and the often, devastating impact, are brand new for the stroke survivor and their loved ones. Many of their needs may only emerge over time and will vary greatly – from ongoing medical needs to more difficult to define social or emotional needs. And each person's stroke will have had a unique impact on their physical, cognitive and emotional wellbeing and abilities.

The huge variety of needs of stroke survivors complicates things further: some localities may have well set up and resourced community rehabilitation services, while other areas may not; a wealthy stroke survivor may be able to absorb the increased costs of living with a disability more easily than someone from a poorer background, for example.

For these reasons researching and providing adequate care to support the needs of stroke survivors and their carers is far from straightforward. This report, based on a comprehensive review of the literature, highlights these issues.

> 'Fundamental skills, like walking or talking, are a big challenge. Aphasia can affect all aspects of communication, including speaking, understanding, reading, writing and using numbers. So the right support can be real lifeline.' **Alexia, Cyprus**

We found that there are very few studies that provide estimates of stroke-related disability, functioning and health trends in adults living with stroke in Europe. There is not even a Europe-wide accepted definition of the longer-term needs of stroke survivors (such as a definitive list of potential needs). And where there is research it is concentrated around the physical health needs and functional abilities of stroke survivors rather than other areas of need – especially on social and economic issues.

This report does not seek to impose a particular definition of post-stroke long-term needs. The wide variety of definitions and methodologies in the research and systematic reviews we found is, perhaps, one of the reasons that estimates of the extent of needs can vary widely. For example, we say that the proportion of stroke survivors with sleep disorders ranges in studies from 13.0% to 94.0%. The different studies captured in a systematic review may have been about specific sleep disorders, may have had different measuring criteria, or recruited a specific group of stroke survivors. While we are unable to describe or to account for these variations, it is clear that sleep disorders are an important unmet need for stroke survivors and that there is an urgent need for more research into interventions that might help to address this.

We wanted to make sure we searched for and found research that covered as wide a range of needs as possible. We aimed to cover topics spanning characteristics of the individual, relationships, the community, and the environment (including physical, socio-cultural, and political components) and other external influences such as available, accessible, and applicable quality scientific information.

Body functions needs

‘In my long-term, still ongoing recovery I have a strong need for continued physio- and occupational therapies. And it goes without saying, that for all of this to happen there is a need for financial resources.’ **Jurg, Switzerland**

‘There needs to be funding through the national stroke plan for specialist therapies for stroke survivors, and proper information for care-givers about how to get training, help and relevant advice.’ **Dorina, Bulgaria**

‘There is more than one important need in relation to living my life with stroke. The one thing that I can’t live without is my wheelchair. It will get me anywhere and I can save myself from painful walking. Next to my chairs, my pain-relieving medication (Lyrica for neuropathic pain, Botox - botulinum toxin and baclofen for spasticity, intravenous pain relief for muscle pain and occasionally Paracetamol to wrestle the neck and backpain, is a necessity in my daily life.’ **Greta, Norway**

Emergency and acute treatment for stroke seeks to address the impact stroke has, minimising brain damage and maximising a person’s potential recovery through timely specialist medical care and rehabilitation. Most recovery from stroke takes place in the first 12 weeks and slows thereafter. But about half of all stroke survivors live with permanent or chronic disability. Some of that disability is visible, but many of the impacts are not immediately apparent. All these impacts can be expressed as needs and the challenge is to find interventions that help to meet or ameliorate them.

We discovered systematic reviews that reported on the following bodily functions:

- Cognitive impairment
- Sleep problems
- Problems with attention, memory and perception
- Emotional and psychological impacts of stroke
- Sight and hearing
- Chronic pain
- Chronic pain
- Mobility
- Continence
- Sexual function
- Aphasia
- Swallowing.

Cognitive impairment has been reported to have a prevalence of over **50.0%** in patients six months post-stroke with one systematic review reporting that **22.1–78.4%** of people living with long-term stroke report unmet cognitive needs. The evidence for interventions such as occupational therapy is inconclusive. **Problems sleeping** are common after stroke. One systematic review and meta-analysis found that the prevalence of post-stroke insomnia ranged between **30.0% and 51.0%** depending on how insomnia was assessed. Other sleep problems such as sleep apnoea or excessive day time sleepiness ranges in various studies, with one reporting it affects over **90.0%** of stroke survivors. Limited medical treatments are available and tend not to be effective long-term although managing emotional problems may help with sleep disorders that are linked to depression and fatigue.

Problems with **attention and memory** are also common - a systematic review of survey studies found that between **22.1% and 78.4%** of stroke survivors report long-term unmet needs related to memory/ concentration/ attention. Many stroke survivors also suffer from **anosognosia**, which makes them unaware of their neurological problems or other problems such as mental health issues and spatial neglect (or inattention) where a person is unaware of the side of their body affected by stroke and the space around them on that side. **Spatial neglect** can interfere with participation in rehabilitation activity. **Impaired executive function**, where planning, working memory, time management and self-organisation are impacted appears to most affect older survivors and has implications for safe and effective participation in rehabilitation and activities including driving.

Stroke often leads to ongoing **psychological and emotional needs**, both because of changes in the brain and the traumatic and sudden changes in people's lives. Depression and anxiety are common with between **20.0% and 25.0%** of stroke survivors suffering ongoing **anxiety**. These rates remain relatively constant, even after two years. Almost one-third **(31.0%)** of survivors develop **depression** in the five years following their stroke. Despite receiving some forms of ongoing stroke care, one review found that many stroke survivors reported management of low mood, managing perceptions of others and feelings of inadequacy and uncertainty related to stroke, medical care, and life as a persistent problem. Trials of pharmaceutical, psychological, complementary, or alternative therapeutic interventions for both depression and anxiety have not been robust enough to conclude whether they are effective.

Other psychological impacts of stroke include **mood problems, feelings of insecurity, psychosis, emotionalism, and disinhibition.**

But perhaps the most important is **suicidal feelings**. A meta-analysis of 10,400 peoples' data found that an estimated **one in eight or 12.5%** of stroke survivors had suicidal ideation and that stroke survivors' **risk of suicide attempt and death by suicide** is around **twice** that of the general population. Those with depression, recurrent stroke, physical impairment and cognitive impairment were more at risk. Another systematic review identified the same risk factors and found that suicide risk is particularly high in the first five years following stroke. There has been some research into pharmacological interventions but the timing and forms of interventions are not clear.

Between **18.0% and 64.0%** of stroke survivors report **vision/ sight-related difficulties** as an unmet care need and a systematic review of qualitative studies reported sight as a persistent problem whether or not people were receiving stroke care. Visual problems include **eye movement and eye position problems** including squint, scanning problems, gaze palsies, nystagmus, double vision, eyelid problems and loss of the ability to see in three dimensions. These eye movement and squint problems can cause double vision, blurred vision, loss of depth perception (3D vision) and can make it difficult for people to read, scan their environment, have coordinated control of eye movement with hand movement and take part in rehabilitation activities. The literature does not reveal any successful interventions.

Stroke can cause a person to lose part of their usual **field of vision.** Types of visual field loss include hemianopia central and peripheral blind spot (scotoma). Visual field defects are estimated to affect **20.0% to 57.0%** of people who have had a stroke, but qualitative and survey research suggests that many do not receive early vision assessment or treatment.

Consequences include unintentional injuries and reduced participation in/exclusion from activities such as reading or driving, with negative impacts on confidence, socialising and independence. A Cochrane review from 2019 on visual field defects concluded that ‘there is insufficient evidence to reach any generalised conclusions about the effect of restitutive interventions or substitutive interventions (prisms) as compared to placebo, control, or no treatment’.

While problems with **hearing** after stroke are less frequent than problems with vision, one systematic review reported the long-term prevalence of unmet hearing-related needs at **6.2%**.

Persistent or **chronic pain** is relatively common after stroke. One systematic review reported that between **14.1% and 54.0%** of stroke survivors report pain-related needs as an unmet care need and a second found **9.1% and 54.2%.**

> ‘Pain can make anyone’s day go south, but I choose to not let it. Most days. The days I have to challenge the “tiger” I need to knit a lot or keep as occupied as I can in other ways. Especially my brain.’ **Greta, Norway**

Central post-stroke pain (CPSP), (also called thalamic pain syndrome) is a long-term condition that causes stroke survivors to suffer from chronic pain and temperature changes. Between **22.0% and 42.0%** of individuals between one month and one year of stroke onset suffer CPSP and **3.0% to 8.0%** of survivors develop CPSP more than a year after their stroke. A systematic review of literature and meta-analysis on the incidence, types and nature of post-stroke pain is currently underway. A review of the management of CPSP concluded that there was no good evidence for effective treatments.

The prevalence of persistent **post-stroke headache** ranges from **7.0% to 23.0%**, with follow-up times ranging from three months to three years after stroke.

Shoulder pain is estimated to impact **22.0% to 47.0%** of stroke survivors. It has been found that prevalence varies across geographical regions, which may perhaps be related to the level of available development and diagnostic services.

Reduced **mobility** on one side of the body is a well-known impact of stroke. The general medical consensus suggests that improved mobility is very hard to achieve after 12 months following a stroke. Evidence suggests that for many stroke survivors, particularly older people, their mobility can deteriorate. (See rehabilitation paragraphs under Systems of Care below). The two main causes of mobility problems are spasticity and muscle weakness.

Spasticity, an unusual tightness, stiffness, or pull of muscles is an unmet need for between **14.7% and 56.6%** of stroke survivors. The prevalence of spasticity after stroke has been estimated at **25.0%** (9-10% disabling or severe). **Muscle weakness** (or sarcopenia) affects **42.0%** of survivors though it is more common in the early phase post-stroke. One systematic review found that upper limb impairments continue to develop over at least three to six months. Exercise can help to build muscle power so should be a part of stroke rehabilitation.

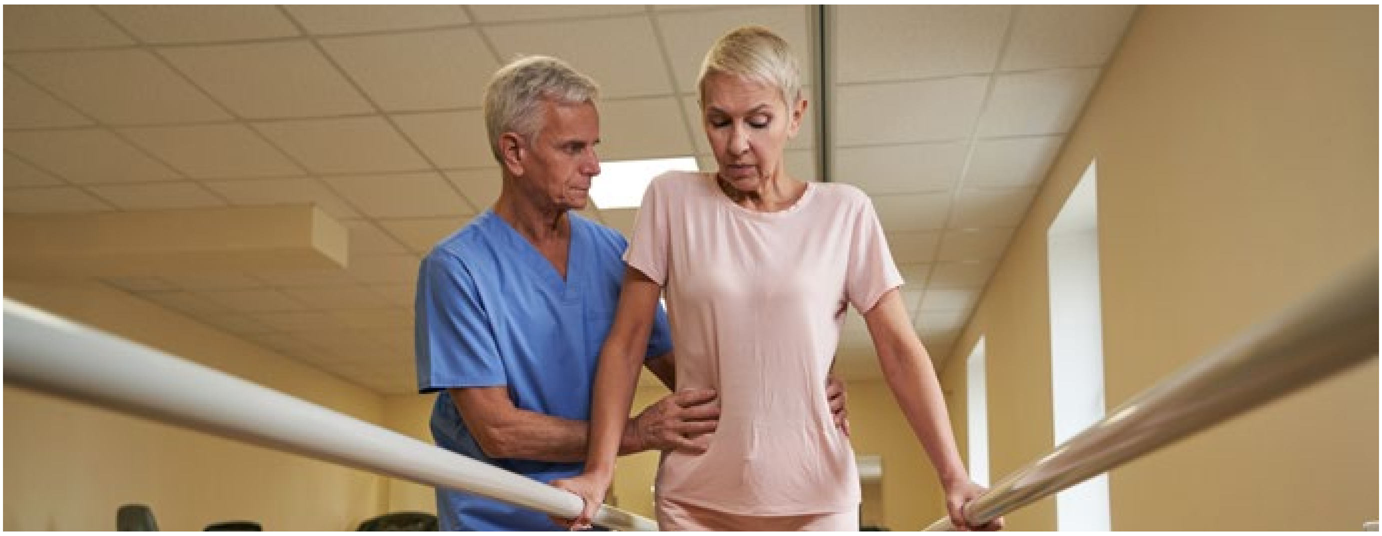
Although most studies do not distinguish between faecal and urinary **incontinence**, the literature indicates that **15.0% to 27.0%** of stroke survivors having persistent urinary incontinence at one-year post-stroke and between **4.8% and 52.0%** of stroke survivors report unmet continence/ constipation care needs. Incontinence negatively affects quality of life, for example, by limiting activities outside the home and also has a significant economic impact on the survivor and wider society due to the cost of care and supplies. The latest Cochrane review concludes that there is little evidence from stroke-specific trials to inform management/ treatment practice, and the evidence is generally poor quality though challenging assumptions that post-stroke incontinence is inevitable seems to be a key component of training interventions.

There is limited data from survey research to estimate the prevalence of **sexual problems**/ concerns and need for support after stroke although prevalence of erectile dysfunction post stroke has been estimated at between **32.0% and 78.0%**, with male survivors having a risk three times that of the general population. A recent Cochrane review concluded that further research is needed to test treatments (pharmacological, therapeutic, psychological) for sexual problems after stroke.

Problems with speech and voice (**aphasia**) are common for stroke survivors with one systematic review reported that between **25.0% and 52.0%** of survivors in rehabilitation or community settings are affected. Another systematic review reported that between **27.9% and 58.4%** of people living with long-term stroke report unmet speech needs and **9.8%** report unmet speech and talk needs. Speech and language therapy is usually available in hospital settings and, to some extent, after hospital discharge.

> ‘To interact socially with others, which incidentally is also important for my sense of self-worth, I need my interlocuters to give me the space and time to let me express myself. Even some of my medical professionals can’t help but finish my sentences despite knowing of my aphasia and need for time to respond.’ **Jurg, Switzerland**

Stroke survivors can also be impacted by ongoing **swallowing problems**. Between **11.6% and 44.0%** report unmet swallow-related care needs. The best evidence on swallowing therapy relates to survivors up to six months after stroke; this shows that therapy can improve swallowing but does not appear to reduce death or disability.



Strokes can cause secondary conditions to arise including:

- Contractures
- Falls
- Fatigue
- Seizures.

Although it is well recognised that **contractures**, the permanent shortening of muscles, tendons, ligaments or other tissues, often leading to deformity and very stiff joints can be a consequence of stroke, we found no systematic reviews on the prevalence of contractures in or reporting contracture-related unmet needs.

Similarly, there is little data on **falls** prevalence, although it seems that stroke survivors are more at risk than the general population. Risk factors for falls include balance and mobility problems, requiring assistance with self-care, use of sedative or psychotropic medications, cognitive impairment, depression, and falls prior to stroke. One systematic review found that between **21.0% and 71.0%** of stroke survivors report falls as an unmet care need. Exercise may reduce the rate of falls, but it is unclear whether this is an effective intervention in the longer-term; there is insufficient evidence to say whether other interventions, such as alternative spectacles, are effective.

Between **34.3% and 75.0%** of stroke survivors report **fatigue** as an unmet care need. Fatigue has been linked with poor mental health and negatively affects return to work rates. Few studies have assessed fatigue at longer time points (for example, 12-, 18-, 24-months post stroke), and longitudinal studies show a mixture of recovery trajectories (for example, some show improvement over time, others indicate onset of fatigue some months after stroke). Little is known about the relationship between physical activity, sleep and fatigue. A qualitative study which explored the experience of fatigue found that it could be disabling even when survivors may have recovered reasonably well physically. Lack of acknowledgement of post-stroke fatigue (by the survivor and others) may make it more difficult to cope and result in increased emotional distress.

> ‘During the first few years(after my stroke) I could only function, communicate and physically do things for one or two hours before having to rest for a good chunk of an hour. Today my stamina, both mentally and physically, is much stronger. There are even days when I can go without a nap during the day though I am still physically and mentally exhausted after about 5 to 6 hours.’ **Jurg, Switzerland**

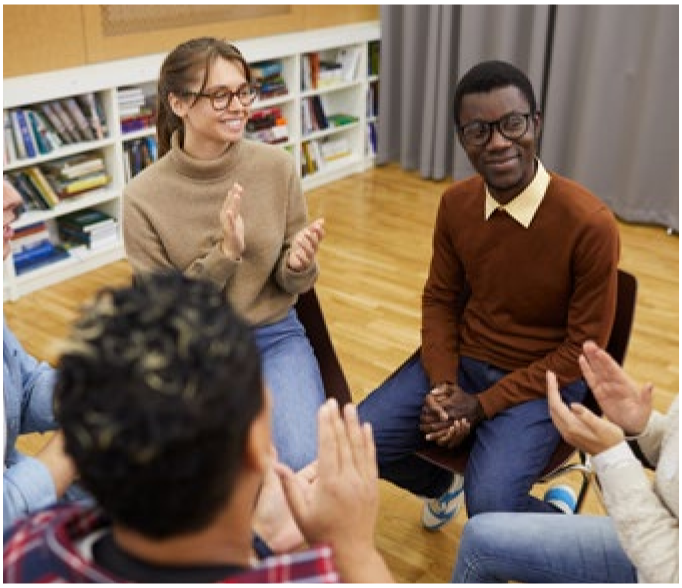
Seizures following stroke seem to be a relatively minor long-term unmet need for stroke survivors. One systematic review reports that **0.2%** of people living with long-term stroke report unmet seizure-related needs. Seizures following stroke seem to be a relatively minor long-term unmet need for stroke survivors. One systematic review reports that 0.2% of people living with long-term stroke report unmet seizure-related needs.

Activities and participation needs

So far, we have focussed on the impact that stroke can have on bodily functions, but not on the way that these impairments affect the ability of stroke survivors to be active and participate in daily life. Meeting these needs should be the key to helping to ensure that stroke survivors can enjoy as good a life as possible.

In this section we briefly cover:

- Listening and reading
- Communication
- Activities of daily life
- Community mobility
- Self and personal care
- Domestic life
- Employment
- Economic self-sufficiency
- Community life
- Staying healthy
- Diet and nutrition
- Aspirational needs.



While we found no reviews of listening problems, survivors' experiences of and the impact of music/audiobook listening has been investigated and a systematic review found that all the studies included demonstrated benefits of music listening on at least one measure of cognition or mood. Reading difficulties affect between 12.0% and 34.0% of stroke survivors.

Up to a third of people with stroke experience communication difficulties including difficulty speaking, writing, and understanding language, both verbal and written (aphasia), difficulty producing speech because of muscle weakness or poor muscle control (dysarthria) or may have difficulty saying what they want to say correctly (apraxia).

One systematic review identified six descriptive themes:

1. Coming to terms with the loss of communication
2. The loss of communication and the loss of identity
3. Isolation and exclusion from social situations
4. A support network of family of family and friends
5. Strategies to facilitate successful communication
6. Activity and meaningful participation in life and highlights the effect of communication difficulties on mood, social relationships and activities of daily living.

> 'I had a haemorrhagic stroke in 2015. It took some time to get familiarised with my disability and develop ways of adapting, coping and solving problems. The most important need is connection with stroke survivors and their needs. The right information is necessary to identify and address health needs.' **Alexia, Cyprus**

3. What we found

Several qualitative research studies have explored stroke survivor and carer experiences of communication difficulties, demonstrating that these can reduce independence, social connections, and participation in meaningful activities.

One systematic review found that between **4.8% and 58.0%** of stroke survivors report communication needs as an unmet care need and a second reported that between **27.9% and 58.4%** report unmet speech needs, **9.8%** report unmet speech and talking needs, **6.2%** report unmet hearing needs, between **33.9% and 69.3%** report unmet reading needs, and **48.0%** report unmet writing needs. Between **27.9% and 58.4%** of people living with long-term stroke report unmet **speech** needs. Several reviews of interventions targeting aphasia and conversation abilities are available; with pharmacological and non-pharmacological options having demonstrated benefits from six months after stroke. Intensive aphasia therapy has been shown in case studies to improve, for example, reading, writing and working memory skills in the long-term, but this intensity is not available to most survivors.

Between **5.0% and 51.2%** of stroke survivors report unmet care needs related to **activities of daily living (ADL)**. A systematic review of qualitative studies reported performing ADL and non-care activities as a persistent problem, expressed by stroke survivors despite receiving some form of post-stroke care.

Community mobility is defined as the ability to move around in the community and using public or private transportation, such as driving, walking, bicycling, or accessing and riding in buses, taxi cabs, or other transportation systems. A systematic review compared the extent to which stroke survivors achieve community mobility when compared to people of the same age or people who had non-neurological health problems. It reported that stroke survivors have very limited community mobility with average scores ranging from **30.0% to 83.1%**. Another found that **16.5%** of people living with long-term stroke report transport-related unmet needs. Stroke can impair ability to drive or prevent driving altogether. However, not all stroke survivors are at increased risk of involvement in an accident while driving. A limited range of interventions (such as driving simulators) has been trialled, and there is limited evidence regarding on-road driving skills.

39.1% of people living with long-term stroke report unmet need related to **arm function.**

And another found that **19.6%** of people living with long-term stroke reported unmet needs related to walking. And between **3.3% and 17.1%** of stroke survivors report unmet **wheelchair-related needs. Driving** is an unmet need reported by **9.8% and 19.1%.**

Between **31.1% and 63.1%** of stroke survivors report **self-care** as an unmet care need, although the definition of self-care used is unknown. One systematic review found that between **17.0% and 50.0%** of stroke survivors reported unmet **personal care** needs.

Domestic life can be a struggle for stroke survivors. Between **5.0% and 39.0%** of stroke survivors report home adaption/ help-related needs as an unmet care need and between **4.7% and 39.3%** of people living with long-term stroke reported unmet need related to home care services. Managing home and family are persistent problems, including the need for help in homecare and following appointment dates.

Stroke survivors list returning to **employment**, getting information about return to work, and strategies to support survivors at work as persistent problems. Between **10.5% and 60.0%** report work-needs as unmet. There are studies on predictors and elements of rehabilitation which support return to work, but there has been less research on the longer-term experiences of stroke survivors who return to work. Reviews have reported rates of return to work (estimated rates vary, partly due to study methodology), time frames for return to work (from three to six months to three+ years) and factors associated with successful return to work. The impact of impairments on employment experience may reduce over time as survivors adjust. There is also some evidence that young stroke survivors experience an increased risk of unemployment (compared to peers who have not had a stroke) several years after stroke. Men are more likely than women to return to work, and survivors who are white, in non-manual occupations and have higher levels of education are more likely to return to work.

While visible or serious impairments are a barrier to return to work, stroke survivors with mild or no obvious impairment may find returning to work challenging. Challenges may include experiencing alienation, discrimination and harassment. One qualitative study (participants between three months and eight years post stroke) also noted fears about coping (for example, with fatigue, stress), and negative reactions to enforced retirement or career change. There are also organisational barriers such as understanding the social welfare/benefits system.

A study of online forum for stroke survivors/carers identified several barriers to staying in work. These included a lack of understanding of stroke (among survivors, employers, GPs) including of invisible impairments such as problems concentrating; and a lack of support in terms of ‘reasonable accommodations’/ adjustments or feeling supported. Participants described solutions including self-motivation, pacing/gradual return/fatigue management, dealing with problems such as depression, self-practice, interpersonal skills, and lifestyle changes.

There is limited evidence that rehabilitation increases rates of return to **employment.** There is low quality evidence (from one trial) suggesting that effective components of employment rehabilitation include neuropsychological services, social work, physical therapy and speech therapy. Studies have highlighted that return to work can be a very varied experience, with role status, working patterns/hours and income all impacted. Differences in definition make it difficult to compare and combine intervention effects.

The ability to be **economically self-sufficient** is an important issue with between **6.0% and 71.0 %** of stroke survivors reporting unmet finance needs. A second systematic review reports that **17.8%** of people living with long-term stroke report unmet financial/ benefit-related needs.

> ‘I have been lucky. But the vast majority of stroke survivors has to live on a much smaller budget than me and have fewer opportunities for reintegration into the work force. I wish for every stroke survivor to have personalized, long-term, multi-year therapy and, above all, a rehabilitation plan.’ **Jurg, Switzerland**

Enjoying **community life** is a struggle for many stroke survivors. One systematic review reported that between **12.5% and 37.3%** of people have unmet needs relating to holidays and between **8.3% and 64.4%** report unmet need relating to hobbies and leisure. Stroke survivors expressed the need for more information about organising holidays that would suit their needs. Between **17.0% and 34.0%** report intellectual fulfilment as an unmet need.

Staying healthy can also be a challenge for stroke survivors. Secondary prevention that can reduce the risk of a stroke survivor having subsequent stroke are a vital component.

One systematic review found that between **9.3% and 77.0%** of stroke survivors report **secondary prevention** as an unmet care need. One systematic review identified long-term (>12 months) unmet need for information on stroke secondary prevention as well as tailored follow-up by health professionals. Another reported insufficient stroke-related information (i.e. stroke prevention, stroke risk, cause of stroke, stroke recovery and secondary prevention) as a persistent problem, expressed by stroke survivors despite receiving some form of post-stroke care. The review highlighted inadequate information about stroke care and treatment, management of stroke complications and identifying sources for stroke care.

A meta-analysis of post-stroke medication adherence and persistence rates found that **26.0% to 33.0%** of survivors, more than 12 months post-stroke, were not adhering to a prescribed medication regime, indicating unmet need for risk reduction among many stroke survivors.

One qualitative study found that the timing and approach taken to providing (usually) written information about secondary prevention (for example, while in hospital, without reinforcement or a discussion involving carers) was often unhelpful. The study identified barriers to behaviour change such as access to appropriate resources and lack of self-efficacy, and barriers to effective information giving such as healthcare professionals lacking skills. It notes that family-based approaches have shown promise in lifestyle interventions in other groups.

Levels of physical activity in stroke survivors are generally low. One systematic review found an estimated **13.4%** of survivors have long-term unmet need relating to **exercise** despite reliable evidence that cardiorespiratory and mixed training reduces impairment. It improves fitness, balance and walking. Stroke impairments, the meaningfulness of the activity to the survivor and their sense of self-efficacy, social support/networks, and their activity level pre-stroke can impact exercise for stroke survivors.

Between **4.4% and 63.3%** of stroke survivors reported unmet needs around **diet and nutrition**. There is little data relating to people’s diets before or after stroke. A review considered the role of diet in post-stroke chronic diseases such as osteoporosis and anaemia; evidence for neuroprotective diets; the link between nutritional status and functional recovery; and the evidence for nutritional supplements such as vitamin D.

Another recent review found a lack of certainty whether dietary interventions reduce recurrent stroke incidence or risk factors. It concluded, however, that the Mediterranean-style diet showed the most promise. Dietary intervention trials are very difficult to conduct properly and interpreting the results is problematic. The review notes that ‘post-stroke impairments including arm weakness, communication difficulties, fatigue, and cognitive difficulties make adherence to dietary interventions problematic’.

Although we did not identify any systematic reviews of community-based studies estimating prevalence of problematic use of substances such as alcohol, tobacco or illicit drugs, one systematic review found reports from people living with long-term stroke of unmet need relating to alcohol use **(5.4%)** and smoking **(7.6%)**. Few smoking cessation interventions have been targeted at stroke survivors. These have included advice and nicotine replacement therapy. Sample sizes tended to be small and patients were recruited from clinical settings rather than the general stroke population. Although pharmacotherapies have evidence of effectiveness in the general population, the evidence in this patient group is unclear.

Research indicates that stroke can disrupt the balance of activities in daily life (for example, work-related vs leisure activity), particularly for working-age people, reducing perceived satisfaction with life but also their **aspirations.** One systematic review of qualitative studies of the patient experience quoted a stroke survivor: ***'We must continue to do what we were doing before, activities or anything else, if we are able to'*** and ***'We need to be able to try and get back at it [work] as soon as we can'.*** One systematic review reports that a range of factors influence participation in life situations, but the literature tends to focus on the biomedical (evidence shows that all body function impairments can affect participation) rather than the environmental factors.

One systematic review of qualitative studies reported that the need to return to the pre-stroke life, to as much extent as possible, was ummet. Survivors' need to accomplish goals or tasks or resolve problems, for example, ***'I would like my gait pattern to become more natural to be able to perform previous activities without assistance...'***. Support to create a meaningful role is identified as a long-term need, particularly among those with communication difficulties. Some interventions explicitly aim to help survivors rebuild a meaningful life, for instance by supporting engagement with leisure and social activities. Peer support or lifestyle groups can help survivors re-engage in meaningful activity and interventions such as arts-based therapies have been reported to potentially improve social engagement, self-esteem and confidence.

Emotional support is also important. One systematic review reported unmet need for support to reduce feelings of abandonment or isolation, and for changes in others' behaviour towards them to reduce embarrassment. For example, ***'it's embarrassing if you go out to a meal. . .yes, I mean, people look at you and wonder. . .like has she got to have her food cut up'.***

Relationships needs

Between **3.3% and 32.8%** of stroke survivors report that needs relating to relationships within family are unmet. A survey found that **two-thirds** of carers reported difficulties in their **personal relationships** with a spouse or partner because of stroke. Of these, **one in 10** had ended the relationship, or considered doing so. The extent of stroke's impact on separation and divorce rates is not known. A systematic review concerning how marital relationships change after stroke describes chaos and the work needed to rebuild or adjust the relationship. Too often sexuality may be perceived as an irrelevant topic for people who have had a stroke, or as difficult to approach in conversation by healthcare professionals or between partners. One systematic review of qualitative studies reported stroke survivors expressing the need for information to resume physical intimacy.

There is limited data from survey research to estimate the prevalence of sexual problems/concerns and need for support. Studies have reported survivors' experiences of resuming sexual intimacy in a changed body, and the ways that barriers to open discussions may be compounded by communication impairments. A recent Cochrane review concluded that further research is needed to test treatments (pharmacological, therapeutic, psychological) for sexual problems after stroke.

A review of **parenting after stroke,** which identified mainly qualitative research, found that survivors usually reported limitations in parenting related tasks and activities such as socialising with other parents. The review notes that stroke survivors who are parents are more likely to need to resume parenting duties at some level than return to work; yet preparing for a return to family life has not had as much research attention as vocational rehabilitation.

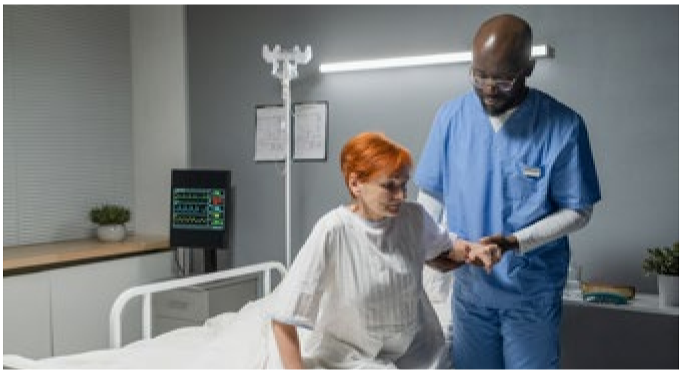
Provision of care needs

> ‘Understanding of stroke survivors needs to come higher on the ladder of both locally based health and social care systems and in the governmental plans. We are often left alone with the system and far too many stroke survivors don’t have the accessibility to adequate care.’ **Greta, Norway**

Stroke survivors and their carers are often reliant on support from health and social care services but too often the systems of care are simply not in place, or are too stretched to provide much support.

In this section we briefly cover:

- Information
- Secondary prevention
- Primary care
- General health services
- Rehabilitation
- Social services
- Voluntary organisations.



To access services, stroke survivors and carers need to be aware of what services are available to them and be able to communicate effectively with healthcare professionals (this might be limited by cognitive and/or speech and language impairment). One study indicated that post-discharge, survivors’ access to social and financial resources can affect their experience of care. Relationships with healthcare professionals and access to health services are among factors which can help or hinder survivors’ efforts to adjust to life after stroke.

Access to **information** is fundamental to the process of patient empowerment. **22.9%** (3.1–65.0) of people living with long-term stroke report unmet need relating to information. Insufficient information is a common theme in systematic reviews, with topics ranging from symptoms, treatment, and prognosis, to short and long-term rehabilitation goals, to writing wills. One systematic review of qualitative studies reported insufficient stroke-related information (i.e. stroke prevention, stroke risk, cause of stroke, stroke recovery and secondary prevention) as a persistent problem, expressed by stroke survivors despite receiving some form of post-stroke care. The review highlighted inadequate information about stroke care and treatment, management of stroke complications and identifying sources for stroke care.

> ‘I have been lucky. But the vast majority of stroke survivors has to live on a much smaller budget than me and have fewer opportunities for reintegration into the work force. I wish for every stroke survivor to have personalized, long-term, multi-year therapy and, above all, a rehabilitation plan.’ **Jurg, Switzerland**

Secondary prevention support is found wanting. One report on the burden of stroke in Europe (using evidence from a European study of ischaemic stroke survivors from 6-36 months after their stroke) showed that **44.0% to 65.7%** of participants had uncontrolled high blood pressure (with or without treatment, mixed hospital and community settings). And a meta-analysis of post-stroke medication adherence and persistence rates found that **26.0% to 33%** of survivors more than 12 months post stroke were not adhering to a prescribed medication regime, indicating unmet need for risk reduction among many stroke survivors. Systematic reviews identify long-term (>12 months) unmet need for information on stroke secondary prevention, and tailored follow-up by health professionals. One systematic review found that between **22.1% to 70.8%** of people living with long-term stroke report unmet need relating to secondary prevention.

One systematic review and meta-ethnography reports that people with stroke and unpaid carers feel abandoned because they have become marginalised by **primary care** services. The authors report that the marginalisation arises because of service passivity and misalignment of information provision with needs, which change with post-stroke recovery. The passivity of services was expressed as lack of continuity of care, including lack of (active) follow-up, limited (in scope and time) and delayed access to community services.

A second systematic review of qualitative studies reported unmet need for nursing care, foot care, and medical care (including secondary prevention) as well as managing changes in habit that were related to health and general wellbeing.

Healthcare services in general are not meeting stroke survivors’ needs. One systematic review of qualitative studies examining the unmet needs of stroke survivors reported issues around availability, accessibility, acceptability, and quality of healthcare services provided. One systematic review found that **49.4%** of people living with long-term stroke report unmet needs for post-acute care. One report on the burden of stroke in Europe found little evidence of health insurers or national health authorities offering support with adjusting to life after stroke beyond home adaptations and aids (for example, vocational rehabilitation).

Rehabilitation services are also a problem. The proportion of stroke survivors relying on care and support are reported to vary from **24.0% to 49.0%** depending on age, stroke recurrence, how long it is since the first stroke, and how the disability is measured. Survivors get less rehabilitation (in hospital) than is recommended by expert consensus, and community-based therapies are scarcely available in several European countries. For example, a review indicated that stroke survivors received on average half the amount of rehabilitation recommended by national guidelines and many reported feeling abandoned after leaving hospital.

One systematic review reported that between **8.0% and 78.0%** of stroke survivors report unmet rehabilitation-related needs. A systematic review of qualitative studies reported unmet rehabilitation needs (i.e., occupational therapy namely in hand function and work rehabilitation; and physical therapy’); insufficient stroke-related information with regards to post-stroke difficulties and short-term and long-term rehabilitation goals; and insufficient information regarding ways to continue therapy at home.

According to one narrative review of qualitative and quantitative studies, occupational therapy, physiotherapy, information about the rehabilitation process, goal-setting, and professional support to maintain participation in various life roles are reported among unmet needs by post-stroke individuals (including in people more than 12 months post-stroke). This review also identified that there is unmet need for rehabilitation support focused on return to work among survivors more than six months post-stroke. One systematic review reported that **13.6%** (2.0–35.7%) of people living with long-term stroke report unmet therapy needs; also, **17.1%** (6.9–59.6%) report employment-related unmet needs (the proportion of this that is unmet need for vocational rehabilitation is unknown).

> 'We need more rehabilitation, both at home and as intensive 3-week sessions to keep as fit as possible to tackle our lives as stroke survivors. We need access to more therapy overall. Especially we need to attend to long-term side effects from using our body incorrectly. We need ongoing care and treatment if our quality of life is going to keep steady and not decline.' **Greta, Norway**

Research has identified the benefits of ongoing **rehabilitation** for stroke survivors, for example, in physiotherapy, occupational therapy, and speech and language therapy. An economic analysis has shown that, if offered to all eligible patients, community-based rehabilitation can increase quality-adjusted life expectancy considerably at the population level compared to outpatient care. However, the benefits of rehabilitation are less certain in some activity areas, such as walking outdoors or in the community. New evidence suggests that, with intensive rehabilitation, improvements can be seen more than a year post-stroke. There is also some evidence that much of the functional and motor outcome gains from rehabilitation provided in rehabilitation centres may be lost over the years following stroke, with older and more severely affected survivors particularly tending to deteriorate.

Rehabilitation and recovery encompass more than direct therapies. Self-management is a term used relating to programmes or toolkit which encourage people to improve their ability to manage their own health conditions. Such programmes can help people to change health =-related behaviours such as diet and substance use, improve self-perceived quality of life and improve survivors' experience. Stroke survivors and healthcare professionals may have a different understanding of what is meant by self-management, and there may be unrecognised barriers to survivors taking an active role in their recovery.

Social service support can be vital for stroke survivors and their carers. A systematic review reported that between **13.4% and 20.9%** of stroke survivors had unmet needs for social service support. A second systematic review reported that **10.1%** of people living with long-term stroke report unmet social service-related needs and between **9.0% and 13.5%** report unmet need for respite/short breaks. Respite care services appear to be an understudied topic. A recent European policy report commented that respite care has historically been a marginal or unfamiliar concept in many countries.

Voluntary organisations often provide peer support and other services with very limited resources. One systematic review of qualitative studies reported the need for more support from voluntary organisations, support groups and peers. A systematic review of peer support interventions found that qualitative studies report benefits, such as on social participation or quality of life, but quantitative studies often do not report significant effects on physical or psychological outcomes.

Community and social context needs

Social participation is a commonly reported aspect of meaningfulness in life, and there has been an increase in research into factors which affect social participation by stroke survivors in the last decade or so. This includes some longitudinal research exploring participation in social/leisure activities over several years post-stroke. Negative changes to social relationships are common for stroke survivors, tending toward a contraction of social networks as survivors lose contact with friends.

One systematic review reported that between **9.0% and 68.1%** of stroke survivors report social life/ participation-related needs as an unmet care need. A second systematic review reported that **15.6%** of people living with long-term stroke report unmet need relating to social life, and **21.4%** report unmet need relating to social support. A third systematic review of qualitative studies reported unmet needs in integrating self with community, such as in social activities as well as being able to get around and fulfil communication. A review of community integration and leisure participation interventions identified some positive effects on participation, depression, and health-related quality of life outcomes. Interventions at the civic or societal level of participation were uncommon, and interventions fall short in addressing full inclusion and citizenship of people with stroke.

Built environment needs

Home adaptations are often essential to enable stroke survivors to be safe and as independent as possible within their homes. One systematic review reported that between **5.0% and 39.0%** of stroke survivors report home adaption/ help-related needs as unmet. A second systematic review reports that between **0.7% and 19.2%** of people living with long-term stroke report unmet home adaption-related needs. A third systematic review of qualitative studies reported aids and adaptations and moving to a suitable house as a persistent problem, expressed by stroke survivors despite receiving some form of post-stroke care. One systematic review of qualitative studies reported insufficient information about modifying home as a persistent problem, expressed by stroke survivors despite receiving some form of post-stroke care.

We found no systematic reviews of studies assessing features of the **built environment** that may influence the health and individual behaviours of people with stroke, such as physical activity and healthy eating.

Access to **transport** is also an unmet need. One systematic review reported that between **5.0% and 53.0%** of stroke survivors report unmet transport-related needs. Another review of qualitative studies reported issues including limited access to transportation; reserved seats for disabled people on buses and trains taken; and parking spaces for people with disabilities commonly taken. Public transport issues were identified as particularly important for people who were not allowed to drive. A fourth systematic review of qualitative studies reported transportation and traveling around and lack of information about using public transport as a persistent problem, expressed by stroke survivors despite receiving some form of post-stroke care.

Laws, policies and regulations needs

Alongside the social and built environment, legal and political issues affect the potential for survivors and carers to benefit from the knowledge produced by research. We do not know the extent of unmet need relating to legal concerns experienced by stroke survivors. Legal entitlements to health and social care are not consistent across Europe, with different thresholds of need being applied to access services where these exist.

The Stroke Action Plan for Europe 2018–2030 has a target that all stroke patients, survivors and carers have a review of the rehabilitation and other needs at three to six months after stroke and annually thereafter. Similarly, the provision of structured health and social care reviews is recommended in England’s national stroke guidelines. One England-based policy analysis of the

six-month post-stroke review found that there was an unjustified assumption underpinning the review policy that providing patients and carers with information would lead to behaviour change and self-management, whereas a more consistent, targeted/individualised approach was in fact needed. In parts of the care pathway, patients and carers felt unsupported i.e., there was a lack of ongoing support or delays in receiving services.
Stroke survivors reported needs for example, for support to return to work and for information specific to their circumstances; however, such unmet needs were generally not resolved through the review and signposting process.

Science, research, and society needs

The research priorities of stroke survivors, carers and health/social care professionals in the UK were recently identified through a UK Stroke Association/ James Lind Alliance Priority Setting Partnership (https://www.stroke.org.uk/research/priority-setting-partnership). This involved collecting, verifying (against existing evidence) and prioritising unanswered questions about stroke in three categories across the stroke pathway: 'Prevention, diagnosis, pre-hospital and hospital care', 'Rehabilitation and long-term care' and 'General'. The lists of research priorities are available online (https://www.stroke.org.uk/sites/default/files/research/priorities_for_investment_to_improve_stroke_rehabilitation_and_long-term_care.pdf). The Stroke Association wants funders, policymakers and research institutes to increase focus and investment in the priority areas, so that relevant research can be translated to policy and practice.

Social environment needs

Several factors, beyond personal health or impairment, have been identified which influence survivors' reengagement in valued activities. One perspective, the social model of disability, argues that people are disabled by barriers in society rather than by their impairment. Self-management alone may not increase activity/participation if the survivor has little control over the support and services they can access, or policies which affect their lives, or they face stigma/discrimination.

One systematic review of qualitative studies reported lack of a sense of feeling respected in different aspects related to stroke, medical care, and life generally as a persistent problem, expressed by stroke survivors despite receiving some form of post-stroke care.

Carers' needs

> 'Carers should have free access to health checks and consultants regarding stress management. We need assistance in technical logistics, transportation and delivery of some vital products, accessories and medicines in order to save time, money and to avoid stress. We should have access to therapies like art therapy, physiotherapy and psychological help in order to avoid burnouts and high level of stress.' **Dorina, Bulgaria**

In this section we briefly cover:

- Educational needs
- Own aspirational needs
- Financial support and security needs
- Ongoing support needs
- Emotional needs
- Managing a family and the home.

Educational needs of carers of stroke survivors are too often unmet. We found three systematic reviews highlighting carers' educational and information needs. These include:

- Information concerning stroke prevention
- Stroke outcomes, especially aphasia
- Services available including rehabilitation and how to access service
- Sources to apply for help
- Strategies to perform activities of daily living
- The practical and emotional aspects of caring for a person with stroke
- The risk of injury as a consequence of caregiving
- How to communicate with the stroke survivor
- How to resume physical intimacy.

We found one literature review reporting the **information, support, and training needs** of relatives of people with aphasia. Information needs identified during the 'chronic' stage include the need for information on aphasia, the complex nature of aphasia, resources to help live with aphasia (including finance and travel), information on therapy and how to continue therapy, strategies to minimise the impact of aphasia on communication at home, information on services available for person with aphasia and family members and how to access them, information on the benefits of rehabilitation in general in addition to therapy (for example, alternative therapies, voluntary opportunities). Other needs identified include the continued need for hope, the need for respite or regular breaks, the need for time off from being the sole communicator in a couples situation, the need for a holiday, the need for a break from new responsibilities, the need for ongoing psychosocial support, the need for emotional support, the need for practical support managing joint affairs and in the event of a decline in the carers heath and need for support to cope with emotional and mental fatigue.

> 'Carers (need) more comprehensive information about a range of topics, not only living with a stroke and the problems that might arise from it, but also on wider issues such as adaptations to property, benefits advice, appropriate exercise, points of contact, opportunities to network, surviving a stroke and preventing further strokes.' **Alexia, Cyprus**

One systematic review reported on the unmet need for carers to balance **own aspirational needs** with caregiving duties. We found two systematic reviews reporting the unmet need for self-care among carers of people with stroke. Unmet needs reported by carers include heightening physical and mental health.

Two systematic reviews report on the unmet need for **financial support and security.** In one review, the authors highlight that limited personal financial resources reduces access to the necessary equipment to meet the needs of stroke survivors (such as equipment to manage incontinence) as an unmet need. Lack of formal referral to social security benefits agencies was also identified as an unmet need.

We found two systematic reviews reporting on carers' unmet needs for **ongoing support.** The authors of one review highlight the changing needs of stroke survivors over time and confusion around the appropriate information and services to approach. The authors of a second review reported the unmet need for support from professionals to support the stroke survivor through the rehabilitation process and to make informed decisions.

> 'As a carer of some who has had a stroke, there is a need for professional help from specialists and carers who can be employed to substitute and support us in everyday activities.' **Dorina, Bulgaria**

Two systematic reviews reported the unmet need to be able to cope and manage the range of **emotions** experienced by carers. Carers reported caregiving-knowledge gaps and lack of 'readiness to care'. The review authors also highlight the unmet need for emotional support and to manage cognitive and behavioural changes in stroke survivors such as mood swings, anger, frustration, and depression. The unmet need for certainty was also identified by the authors of one review. Unmet need for certainty including who would provide care for the stroke survivor in the event of a decline in the health of the caregiver. One systematic review reported on caregiver' need to 'manage changes in the role and relationship' with the stroke survivor and the unmet need for social support from friends, family, and the community.

> 'Identifying and addressing the health needs of carers and family members or friends is needed.' **Alexia, Cyprus**

We found one systematic review reporting the unmet need for support in **managing a family and the home.**

The key themes and recommendations that emerge are:

- There is too little research into the long-term needs of stroke survivors and their carers, exacerbated by a lack of common ways of understanding, measuring and meeting needs, which means that stroke survivors are being left with a range of often very debilitating unmet needs.
  Recommendation: Governments should provide funding to investigate the medium and long-term needs of stroke survivors and the improvements in service provision to meet those needs.

- There is a severe lack of consistent information, preparation and training for stroke survivors and their carers to enable them to understand and best tackle their long-term needs over time.
  Recommendation: Health and social care systems should be designed to high quality information and training for stroke survivors and their carers that is easily accessible over the long-term.
  Recommendation: all stroke survivors should be followed at least annually to have their needs assessed and to be referred to services.

- The provision of community-based rehabilitation therapies and support is falling short of people's needs.
  Recommendation: National and local health and social care systems must improve access to rehabilitation therapies for stroke survivors for as long as they continue to show benefit.

- Secondary prevention advice and support is failing to help people reduce their risk of having another stroke
  Recommendation: National and local health and social care systems must improve the provision of and access to secondary prevention services and support.

- Many chronic symptoms such as memory and concentration problems or fatigue are not well understood, poorly researched and lacking in interventions that work.
  Recommendation: More specialist support is needed post-stroke to help stroke survivors cope with ongoing issues such as chronic fatigue and concentration problems. Much better access to mental health support is vital.

- Carers' needs are under-researched and often ignored in service provision.
  Recommendation: people supporting and caring for stroke survivors should have timely access to information and support, including meeting their needs to 'self-care'.

5. Implications for future research

Based on the findings of this review we have developed more detailed recommendations, which should be considered alongside the research and development priorities set out in the Stroke Action Plan for Europe 2018-30 [2].

1. Towards a deeper understanding of needs and unmet needs

The socio-ecological model used in this review is an example of a tool that research planners, research funders, and care commissioners should refer to as a reminder of the broader needs of people living with stroke and their carers. This means considering needs beyond individual physical and mental function including those which are self-transformative and aspirational. Needs assessments should enable people living with stroke and their carers to identify all needs, not only those which align with the interests of the professionals managing their care or conducting research.

Further work should focus on:

- Needs for which there is currently little stroke-specific research and especially areas such as the built environment, legal concerns, and the social environment. This will require research from a wider range of disciplines and perspectives, for example, social policy and environmental engineering. Examples of broad questions are: What are the features of the built environment that influence the health and individual behaviours of people with stroke? How are people with stroke and their carers affected by and included in legal/policy decisions? (for example, related to employment). How much is known about perceptions of stroke-related disability (among the public, employers, health and social care professionals), and what works to improve attitudes so that people living with stroke are treated with dignity and feel respected?

- Understanding experiences of stroke, and how people living with stroke and their carers prioritise unmet need, at different points in their lives

- Methodologically rigorous studies capturing the unmet needs of people living with stroke and their carers in non-Western European countries, to address the under-representation of these populations in the published research literature.

2. Interventions to address outcomes that are important to people living with stroke and their carers

- Research questions relating to psychological/emotional health, cognitive function, communication and fatigue have been identified as top research priorities by consensus-based priority setting exercises such as those conducted for the Stroke Action Plan for Europe and UK Stroke Association/James Lind Alliance Priority Setting Partnership (involving stroke survivors, carers, health and social care professionals) [https://www.stroke.org.uk/research/priority-setting-partnership].

- This review also highlights evidence gaps relevant to identifying and managing those with stroke at risk of suicide: strategies to identify suicidal ideation, particularly in people who do not meet clinical criteria for depression, and effective interventions. This topic is not generally mentioned among research priorities. This review cites evidence that stroke survivors' risk of suicide attempt and death by suicide is around twice that of the general population, so there is an obvious need for action to prevent this loss of life and repercussions (such as impact on family and friends).

- Priorities for research into interventions to benefit carers should be clarified.

3. The provision of services across the post-acute stroke care pathway

This review and the Stroke Action Plan for Europe cite evidence of gaps in provision across the post-acute stroke care pathway, including in community-based rehabilitation, regular reviews of health and social needs, and secondary prevention.

- Secondary prevention information and services are among the most reported unmet needs, after rehabilitation. Gaps in ongoing secondary prevention care have been identified across Europe, including lifestyle management programmes, access to some medications which help to control clinical risk factors, and face to face follow up in hospital or in primary care.

- The Stroke Action Plan for Europe highlights important contributing factors to gaps in care including a lack of robust data on longer term stroke management/care, and the associated problem of a lack of reference to life after stroke in national guidelines. The evidence presented in this review underscores the need to implement existing evidence-based guidelines and identify models of best practice which can be applied in (other) European countries.