



evolution

**LIVED EXPERIENCES OF  
STROKE FOR BERMUDA 2022**



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***STROKES ARE  
SURVIVABLE***

# TABLE OF CONTENTS

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<b>INTRODUCTION</b>	<b>1</b>
What is a stroke?	1
Context of stroke rehabilitation and Bermuda	1
<b>ABOUT THIS SURVEY</b>	<b>2</b>
Demographic information	3
The Short Form- Stroke Impact Scale (SF-SIS)	4
<b>SURVEY FINDINGS</b>	<b>5</b>
Rehabilitation experiences	5
Support on discharge	7
Gaps in services	7
Barriers to rehabilitation	8
Therapy needs	10
Lack of specialized services and equipment	11
Community reintegration and recovery:	13
Leisure and social engagement: returning to work and financial support	14
Finding support	15
Information on services and communication	15
<b>CONCLUSION</b>	<b>16</b>
<b>REFERENCES</b>	<b>17</b>
Appendix one: Useful contact information	18

# INTRODUCTION

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For this project, a nationwide online survey was conducted to gather data about the lived experiences of stroke survivors in Bermuda. The online nationwide survey was available to any stroke survivor who met the eligibility criteria. We plan to use this data to help us inform what is happening through the stroke pathway and put forth any recommendations that would be useful for survivors and the community. Two researchers completed data analysis (see full report for more information). Quotes are used throughout to illustrate the main points found during this report. Minor adjustments have been made to spelling and grammar ensuring that the sense of the quote remains.

## WHAT IS A STROKE?

A cerebrovascular accident (also known as a stroke) is a sudden life-threatening event that causes damage to the brain (which is the main centre that helps control who we are and what we can do) (Mayo Foundation for Medical Education and Research, 2022). A stroke happens when a part of the brain loses its blood supply through either a clot (ischemic) or bleeding (hemorrhagic) (Ntaios, 2018; Sacco et al., 2013). How a stroke affects each person depends on the area of the brain impacted, how much damage there might be, and the person's status prior to the stroke (Hillis & Tippett, 2014; Nelson et al., 2016). As every stroke is different, it is critical to understand for yourself and your loved ones that many different changes may occur and to ask your healthcare provider for more information (Mayo Foundation for Medical Education and Research, 2022).

Some people might experience challenges with communication (speech, language, understanding), cognition (thinking, organizing, memory, or neglect), physical impairments (weakness, sensory loss, balance, tonal changes), and emotional or personality changes (Nasr et al., 2016; Pinter & Brainin, 2012; Röding et al., 2009). As every stroke is different, it is important to understand for yourself and your loved ones that many different changes may occur and to ask your healthcare provider for more information (Mayo Foundation for Medical Education and Research, 2022). We must support one another as a community because some stroke survivors may experience reduced quality of life, functional abilities, and social isolation (Tsao et al., 2022).

## CONTEXT OF STROKE REHABILITATION AND BERMUDA:

In Bermuda, by 2026, there is expected to be population growth with a rise in the proportion of seniors (65 years and older) (Government of Bermuda department of statistics, 2016). Even with the smaller population size of Bermuda, there is a rising number of stroke incidents (Dyer, 2022; Institute of Health Metrics and Evaluation, 2022). Data collected from the Bermuda Hospitals Board in 2020 reported that there were approximately five incidences of cerebrovascular accidents a week and seven Transient Ischemic Attacks, totalling 261 stroke incidences for the year. Nationally the Ministry of Health has identified stroke as the second leading cause of death in 2019 and the third leading cause of disability in Bermuda (Institute of Health Metrics and Evaluation, 2022). Therefore, prevention and rehabilitation should be one of the leading health priorities due to the growing number of stroke survivors on the island. Currently, there are limited stroke rehabilitation services in Bermuda, although data shows that structured, organized, coordinated, multidisciplinary services can improve post-stroke outcomes (Clarke & Forster, 2015; Langhorne et al., 2011; Prvu Bettger & Stineman, 2007).

## ABOUT THIS S.T.R.O.K.E. SURVEY

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Sustainable Therapy & Rehabilitation Optimizing Kinetic & neuromuscular Excellence

This survey was completed in accordance with Bermuda Research Ethics Committee. The survey aimed to gather the lived experiences of those in Bermuda after having a stroke. The survey ran for eight weeks. During that time, 205 people accessed the online survey, and 56 people completed the survey. Thank you to everyone who devoted their time to complete the survey on stroke rehabilitation and to **AGE Concern** for their ongoing support.

When participating in the survey, the participants chose whether they would like to remain anonymous or be named in the study. We would like to acknowledge and thank those who completed the survey who wanted to remain anonymous and those that did not want to remain anonymous: Stuart Anderson, Merle Bascome, Ivan Swan and his wife, Linda Duncan, Andrew Sampson, Judith A. M. Godfrey, B. A Sinclair, Raymond Marshall, Carlton Dill, Frances Furbert, Chirleen Williams, Arthur Lee Ray, Dennis Ottley and his wife, Robert Croft, Jenene Douglas, Mair Harris, Raymond Charles Latter, Barry Hanson, Stephan Ahknaton, Arthur C Price, Terrance Anthony Norsworthy, William Richardson, Kurt Griffith, Leroy S. Wales, Robina Fullerton, Elizabeth Smith, Malika Watson, and Richard Hawke.



## DEMOGRAPHIC INFORMATION:

 **Who we spoke to:** Located: 95% of the participants currently resided in Bermuda

 **Gender:** 52% male 48% female

 **Type of stroke:** Ischemic 39% Hemorrhagic 14% Unsure 30%

 Of the 42 participants that reported their age was between 19-91 years of age.

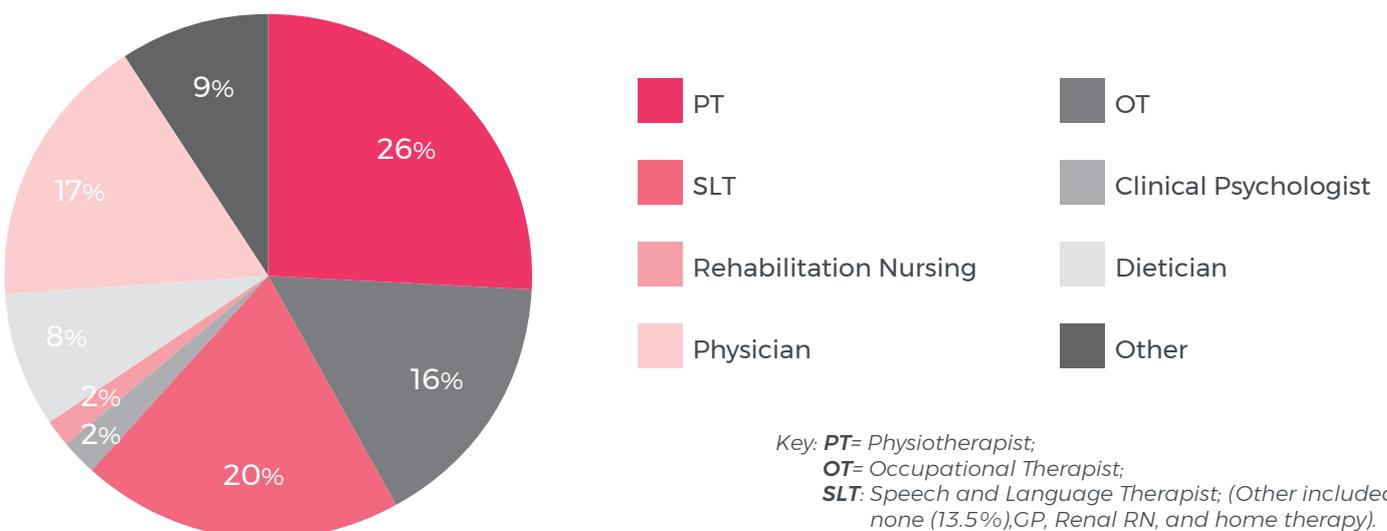
 With the average age being 68 years old;

 64% > age of 65 years of age and 34% under 65 years of age.

## SOME OF THE GENERAL REHABILITATION DATA COLLECTED SHOWED THAT:

The time frame for rehabilitation differed dramatically from 0-1 month to one participant responding for five years. The average timeframe was 11 months. Of the 42 participants that responded to the question, 21% (9/42) of participants felt their rehabilitation needs were met and 79% (33/42) felt that their needs were not met.

## The rehabilitation professionals seen:



## THE SHORT FORM- STROKE IMPACT SCALE (SF-SIS)

The SF-SIS was used to gain information regarding the challenges the participants face daily. The SF-SIS is a stroke-specific health-related quality of life measure, and the questions are designed to detect over the past weeks the impact on their daily life in a broad range of areas (Macisaac et al., 2016). Forty-two participants completed the SF-SIS.



### LEG STRENGTH LOSS

5% could not use  
21% very difficult  
21% somewhat difficult  
29% little difficulty  
24% no difficulty



### THINKING QUICKLY

2% could not  
5% very difficult  
14% somewhat difficult  
29% little difficulty  
50% no difficulty



### NOTHING TO LOOK FORWARD TO

12% nothing to look forward to  
5% very difficult  
19% somewhat difficult  
28% little difficulty  
36% no difficulty



### DIFFICULTIES CONVERSING

0% could not  
2% very difficult  
12% somewhat difficult  
10% little difficulty  
76% no difficulty



### DIFFICULTIES PERFORMING TASKS

24% could not  
7% very difficult  
19% somewhat difficult  
19% little difficulty  
31% no difficulty



### WALKING WITHOUT LOSING BALANCE

24% could not  
9% very difficult  
17% somewhat difficult  
26% little difficulty  
24% no difficulty



### PICKING UP A COIN

22% could not  
7% very difficult  
7% somewhat difficult  
7% little difficulty  
38% no difficulty



### SOCIAL LIMITATIONS

17% could not  
12% very difficult  
19% somewhat difficult  
21% little difficulty  
31% no difficulty



### GOING TO THE BATHROOM

7% could not  
2% very difficult  
5% somewhat difficult  
14% little difficulty  
71% no difficulty



### BLADDER CONTROL

7% could not  
7% very difficult  
5% somewhat difficult  
19% little difficulty  
62% no difficulty



### BOWEL CONTROL

7% could not  
0% very difficult  
5% somewhat difficult  
17% little difficulty  
71% no difficulty

As you can see from the SF-SIS, the needs of each participant varied. The participant's responses ranged from challenges with different aspects such as physical, cognitive, psychological, and social such as engaging in meaningful activities, communication, mobility, hand function, and general health. Due to the unique needs of each survivor, stroke rehabilitation should be a coordinated, multidisciplinary service focusing on returning people as close as possible to their pre-stroke state and previously meaningful activities such as work, education, hobbies and leisure activities, and family or home life duties (American Stroke Association, 2018; Gillen, 2016).

## SURVEY FINDINGS

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The stroke rehabilitation journey from the survey participants' perspective:

“ . *Patient still requires this and a shot at recovery as much as possible.* ”

### REHABILITATION EXPERIENCES

There was a mixture of good and bad experiences during rehabilitation, which was also noted in the demographic results. Some participants described a lack of hope for the future, what to expect after rehabilitation experiences, or knowing when their rehabilitation would stop.

“ . *After rehab away for four weeks, I feel that that is the end of rehab.*  
 . *None was offered or help in knowing what to do in future.*  
 . *When she went to do the physiotherapy at the hospital, they said there was nothing that they could do.* ”

Some participants reported positive rehabilitation experiences and described their experiences with their therapists and in different settings. Many participants who described a positive experience talked about how it was ongoing.

“ . *More enjoyable and useful in outpatient experience.*  
 . *My therapists were very focused, challenging and thorough.* ”



## OVERSEAS REHABILITATION

- *Initial intensive rehab in the US made the most difference.*
- *My therapy began in Boston. Bermuda didn't have the expertise. The therapy was completed in Bermuda.*
- *Came back from overseas and received rehabilitation at the hospital, but then it was stopped.*
- *Yes, going to an overseas rehab, or perhaps BHB should sign an agreement with private local physio facilities to help where they are falling short instead of reducing services.*



## OUTPATIENT PRIVATE REHABILITATION

- *Ongoing physio locally has allowed me to regain partial use of my right arm.*
- *Six weeks (once a week) at Day rehab at the hospital was very poor. I've now done 16 months in outpatients, once a week, and they are very good with their limited equipment.*
- *Rehabilitation was in an outpatient clinic, not at the hospital.*
- *In hospital excellent; outside extremely disappointing.*
- *Had the visiting therapist come to the house and had a fall at home.*
- *BHB was very poor, better when I started with (physiotherapist in outpatients).*



## REHABILITATION IN THE HOSPITAL (BERMUDA HOSPITALS BOARD - BHB)

- *The hospital staff were pleasant, and free services were helpful, but getting signed up was awkward.*
- *At the hospital, the treatment was not enough in 2 weeks.*
- *PT inconsistent /2 HBP was not under control.*

## SUPPORT ON DISCHARGE

Once discharged, some of the participants felt that there needed to be more support. The participants reported that having coordination of services on discharge, as well as improved access to services promptly, was important.

There were suggestions that a case manager may be appropriate to help with this transition and that referrals to the right services were needed.

- “
- *Yes more, and appropriate rehabilitation, and case management.*
  - *Need someone to help with the process of where to go and what to do.*
  - *Physiotherapy, counselling on home care, referrals to services available.*
- ”

## Coordination of services

The participants discussed a lack of coordination between healthcare professionals and the different services. Working together could help to improve the discharge process.

There needs to be:

- “
- *Doctor coordination.*
  - *More coordination with the hospital and community services.*
  - *Holistic, Coordinated Efforts.*
- ”

The need for better and prompter access to services on discharge was an area that needed improving for the participants.

Access to services on discharge:

- “
- *No government rehab at home once released from the hospital.*
  - *Access to outpatient services sooner.*
  - *Did not consistently go to any place long enough.*
- ”

## GAPS IN SERVICES

Many of the participants reported that there were gaps in service for stroke rehabilitation. It was impossible to get treated for everything related to their stroke rehabilitation needs, but some areas were covered (such as cardiac rehabilitation). On discharge from the acute phase, the participants felt there was little coordination or an easy transition when they returned to the community. The participants suggested starting these services once discharged right away rather than having a gap or waiting time before their rehabilitation began.

“  
· *Somewhere to get assistance with the whole recovery. Not in silos.*  
”

There were noted gaps in services for the participants. Some of the participants discussed that the services for stroke rehabilitation were lacking but there was coverage in other areas.

Coverage of services:

“  
· *Did not receive services for stroke but good coverage for other needs.*  
· *But good other needs met for cardiac rehabilitation and other equipment and wound care.*  
· *Not getting rehabilitation for stroke only for the other cardiac problems.*  
”

There is a missing link for the stroke pathway from acute to community services. Many of the participants felt as though there was a gap between services and more coordination was needed. There needed to be access to these services sooner on discharge from the hospital.

Transition of services on discharge and appropriate community management:

“  
· *Daily input, better transition to community services, and more advice in management for family members to help.*  
· *Detailed, specific, and automatic follow-through once at home.*  
· *His wife wishes there was a specific rehabilitation pathway/setup here.*  
”

## BARRIERS TO REHABILITATION

Some of the participants mentioned that there were barriers to them accessing rehabilitation, including the geographical location of their rehabilitation setting and the time it took to get to their appointments. Some participants found it challenging to travel physically to the rehabilitation setting. The participants also noted that their rehabilitation was disrupted or reduced due to shortages of healthcare professionals.

“ . *Client needs much rest in between with the travel to the clinic.* ”

### Location & travel time

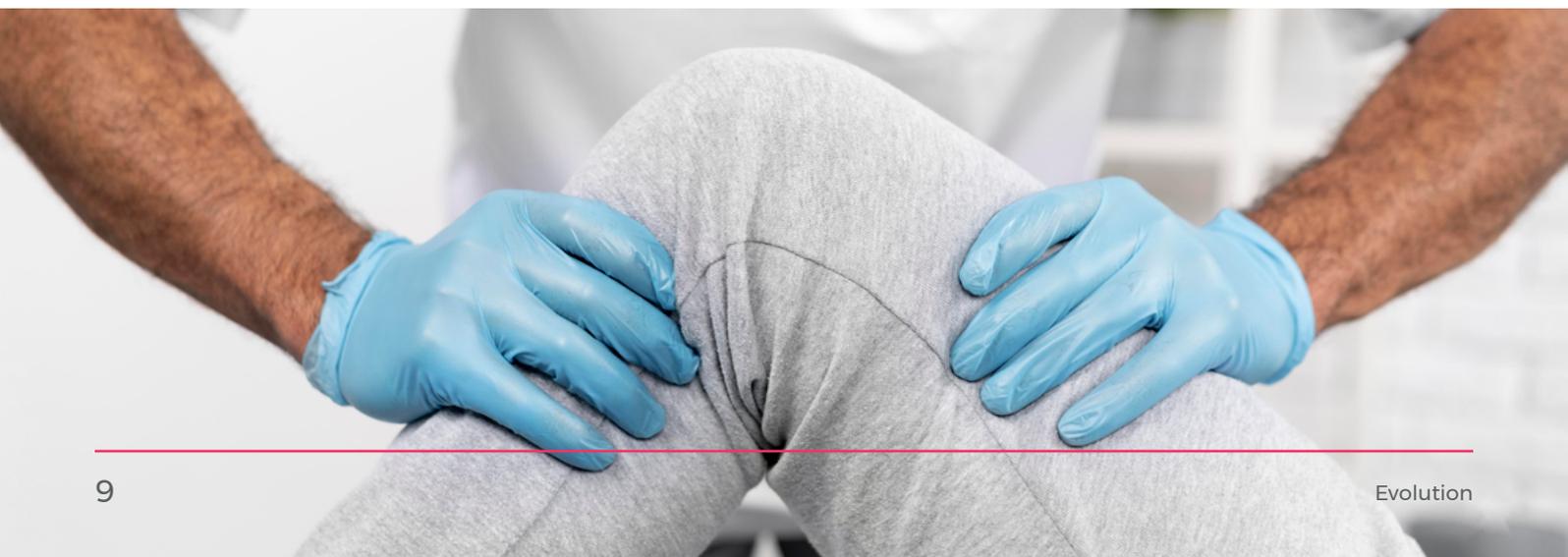
There were specific barriers to rehabilitation, including location and travel to rehabilitation services. Some participants found it challenging to travel to their rehabilitation due to fatigue, and others did not get the opportunity to go to therapy.

“ . *Difficult to get there.*  
 . *To be able to go somewhere.* ”

### Healthcare professional shortages

The participants discussed staff shortages during their rehabilitation and that this impacted therapy.

“ . *Rehabilitation was not enough, and a second person is needed to do the therapy and not always reliant on the family members.*  
 . *My therapists were pressed for time because of chronic understaffing.*  
 . *I had to fight for it, there was a shortage of therapists of all types, and this led to not being serviced as much as I should have.* ”





## THERAPY NEEDS

There was a need for more healthcare professional groups, such as physiotherapists and speech and language therapists. More input for these sessions was suggested. The participants felt their rehabilitation needs were not met with the amount and intensity of therapy. Most participants felt that they wanted more and that more input would be a benefit to their stroke rehabilitation. Many participants reported needing more input from the healthcare professional groups of physical therapy and speech and language therapy.

“ *More intensive therapy earlier on may have allowed more progress.* ”

Many participants felt they needed an increase in the amount and intensity of therapy.

“  
• *Needed more therapy only one time a week for an hour.*  
• *Needed to be much more frequent.*  
• *Felt that he could have had more.*  
• *Not enough rehab directly following the stroke.*  
”

There were specific requests for physiotherapy and speech therapy, with noted gaps in the rehabilitation service.

“  
• *Longer periods of physio and speech therapy.*  
• *Additional physical rehab.*  
• *More time at physical therapy.*  
• *Better SLT (speech and language therapy) support after release from the hospital.*  
”

## LACK OF SPECIALIZED SERVICES AND EQUIPMENT

The participants felt they needed more specialized services, healthcare professionals, and a specific setting for stroke rehabilitation. They felt that not all healthcare professionals had experience working with people post-stroke. Some participants discussed wanting a specific place to complete their rehabilitation, including access to a gym to carry on with their rehabilitation needs.

“  
· *Rushed and generalized, not specific, seems other treatment methods would have been beneficial to specific needs.*

”

## Specialization of services

The participants also felt that there was no specialization of services. Some believed that when they had completed their rehabilitation in Bermuda, the services and healthcare professionals did not have the expertise.

“  
· *Bermuda didn't have the expertise.*  
· *Not specific enough or specialized and needed more.*  
· *Bermuda does not have this type of a facility nor the ability to provide this quality of rehabilitative healthcare.*

”

## Healthcare professional training and expertise

Some of the participants suggested more specific training for healthcare professionals and increased expertise in stroke rehabilitation. The participants felt that having increased experience was needed for those working in stroke rehabilitation and with survivors.

“  
· *Experience and training for stroke rehabilitation.*  
· *Need nurses and rehab persons and equipment specific to stroke and not general treating stroke recovery.*  
· *At the hospital, they need nurses who are trained to deal with stroke patients.*

”

## Specialized rehabilitation setting

The participants suggested a more specific rehabilitation setting would be helpful and a gym setting to practice. Having one place to come and continue their rehabilitation was important.

Stroke-specific rehabilitation centre with gym access:

“

- *Need a modern stroke center with pool/equipment/ services, stroke rehab, etc.*
- *Ability to use rehab equipment in a similar setting to practice exercise - something like a gym but with rehab equipment.*
- *More availability of diagnostic machines and gym appointments.*

”



## COMMUNITY REINTEGRATION AND RECOVERY:

Bermuda is falling short in community reintegration with challenges in access to rehabilitation through a lack of insurance coverage. Improvements in leisure and social engagement are also necessary, including more active support groups. Many of the participants discussed that rehabilitation was costly. The participants talked about how it became too expensive, and they had to stop their therapy or continue doing it without healthcare professional input. There were limits on private services, which reduced the participant's choice of healthcare providers.

### Insurance coverage:

“

- *More therapy paid by insurance.*
- *Paying for payments even when missed and it is costly. Doing outpatient therapy which is helping. Insurance needs to cover more for rehabilitation services. You also need support for the caregivers. The sooner there are changes, the better for a lot of people.*
- *Had to seek out your own treatment and pay out of pocket to continue your rehab.*
- *Insurance needs to cover more for rehabilitation services.*

”

Many participants reported a need for more insurance coverage, especially related to private physical therapy. Physical therapy was not covered after the 12 sessions, and the participants had to pay out of pocket. The participants did not always have a choice to get private physical therapy because it was available in the hospital.

### Coverage for private physiotherapy

“

- *More frequent sessions at the hospital therapy, central hospital, or sire or coverage for private physio.*
- *Cover for private physio was limited to 12 sessions per year, and it got too expensive after that.*
- *Because the hospital service is available, my insurance did not cover private physio beyond the standard 12 sessions.*

”

## LEISURE AND SOCIAL ENGAGEMENT: RETURNING TO WORK AND FINANCIAL SUPPORT

“

- *He had to return to work without rehabilitation.*

”

Some of the participants discussed that it was important that during rehabilitation, financial support was available. The participants also discussed that there were specific needs for those returning to work.

“

- *Funds to support myself during recovery.*
- *Being a fit athletic male in his mid 40's, I needed rehab directed towards someone who could perform basic life skills. I also needed better help transitioning back to work.*

”



## FINDING SUPPORT

“

- *One year on, I am still trying to get help.*

”

Communication and information sharing with patients were needed in Bermuda, and it was found that support through the service was imperative.

Information on services and communication

“

- *It is hard to find what is available.*
- *Communication about the needs and what was happening.*

”

Searching for support

“

- *Yes, just offered statins, and that was it. I wanted a support group and information.*
- *Would like some kind of help or social activity with others in the same situation.*
- *A stroke support group is needed. Need support and sharing. Can share stories and experiences. Using the church support system at present.*

”

The participants suggested support groups were needed for their stroke rehabilitation journey. This support included not only systems and organizations but also from their peers and was also necessary for the caregivers. This suggestion is part of the rehabilitation journey and is as important as the other components of physical rehabilitation.

Stroke support group

“

- *You also need support for the caregivers.*
- *We also need a stroke support group in Bermuda.*
- *Don't know if there is a support group.*

”

## CONCLUSION

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Thank you to those who have shared their experiences of stroke rehabilitation. From the participant's comments, it is clear that some have experienced unmet needs related to their rehabilitation in Bermuda. This survey was the first of its kind that we are aware of, and it is a vital first step in understanding the needs of those living in the community post-stroke. We must continue to push to make changes and improve services related to these needs. In the coming years, rehabilitation needs are expected to rise globally, and many international healthcare agendas are pushing for affordable healthcare coverage, which includes prevention and rehabilitation. Bermuda has the opportunity to be a country of excellence and provide world-class rehabilitation with the right systems, structures and funding.

Proposed changes from this survey report include:

- There should be more insurance coverage for stroke rehabilitation from private insurers and the government.
- There should be an improved stroke care pathway for continuity of care.
- Stroke survivors should have access to specialized multidisciplinary care.
- There should be an increase in the number of healthcare professionals that can deliver high-quality stroke rehabilitation.
- A support group for survivors and caregivers should be established and active in Bermuda.

There is a separate document which provides a proposed stroke rehabilitation pathway from the acute to the community phase. This pathway is suggested from the participants needs and the international guidelines which can be found in the full text report.

Additional information regarding healthcare professionals and services are also provided in appendix one.



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## APPENDIX : USEFUL CONTACT INFORMATION

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### Support groups and organizations:

**Bermuda Stroke & Family Support Association:** Mark Selley (Chairman)- 441-293-3121; 'Seven Sea's,' 6 Rock Garden Lane, Harrington Hundreds, Smith's, FL 06

**Bermuda Heart Foundation:** <http://www.bermudaheartfoundation.com/>

**Age Concern:** <https://ageconcern.bm/>

**Ageing and Disabilities Services:** <https://www.gov.bm/department/ageing-and-disability-services>

**Find a Caregiver:** <https://helpingservices.bm/homecare-providers/>

### Support for meals:

**Meals on Wheels:** <http://mealsonwheels.bm/mow/>

### Transportation and equipment rentals:

**Bermuda Red Cross** (for equipment rentals- 441-236-8277 Novella Waldron; and transportation- 441-292-1276 Helen Nolan): <https://bermudaredcross.com/services/equipment-rental/>

**Access Bermuda Disable Transit / Keith Simmons:** +1 (441) 295-9106, [keithsimmons@logic.bm](mailto:keithsimmons@logic.bm)

**Renalda Bean Snr:** 441-334- 8835, Email: [renetaxi1778@gmail.com](mailto:renetaxi1778@gmail.com) (taxi service that can accommodate a wheelchair)

**Dwight Paul:** 441-332-1019 (transfer services in his wheelchair accessible taxi).

### General classes:

**Seniors Learning Centre (SLC):** <https://www.college.bm/index.php/llc>

### Outpatient rehabilitation services:

**Speech Language Services: Coordinator:** 441-278-6429, Email: [sgbarrett@gov.bm](mailto:sgbarrett@gov.bm) Kimberly McIvor (Apex Allied Health)- Senior Speech and Language Pathologist

**Occupational Therapy Services:** Jill Davidson (Function Junction)- Senior Occupational Therapist. Email: [functionjunction.jill@gmail.com](mailto:functionjunction.jill@gmail.com)

**Physical therapy services:** Evolution Healing Centre: 441 734 2772, [director@bpralliance.com](mailto:director@bpralliance.com)

**Psychology Services:** Susan Adehmar- Clinical psychologist

**Dietician Services:** Island Nutrition Limited: 441-295-4082 <https://www.islandnutrition.bm>



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STROKE FOR BERMUDA 2022**

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