Take Charge for people with conditions other than stroke

A training manual for facilitators



For training, this manual should be used in conjunction with the following resources:

1. 'Take Charge training for facilitators' slide set' available here: https://bit.ly/3ysp1KM (under 'Downloads') or if that internet address changes for some reason try www.mrinz.ac.nz/programmes/stroke

2. 'Sam's Gift' by Harry McNaughton (ISBN-13: 978-1739941307) – a short 'novel' that uses the story of one person to help explain Take Charge for people with stroke and those that are important to them (as well as facilitators!) available in paperback here: https://amzn.to/3z3TD49 or as a free eBook or pdf file here: https://bit.ly/3ysp1KM (under 'Downloads'). You can use Kindle or other free eBook reader apps like 'Aquile Reader' to read it on your phone or computer.

3. 'Being Mortal' by Atul Gawande, especially the second half of the book, is a wonderful introduction to many of the same concepts that underly Taking Charge. In all good bookshops or online eg. https://www.bookdepository.com/Being-Mortal-Atul-Gawande/9781846685828

Take Charge is effective for people with stroke, with evidence from two large randomised trials. Take Charge has been used with people with conditions other than stroke – in particular Chronic Obstructive Pulmonary Disease (COPD), traumatic brain injury, spinal cord injury and early dementia. Evidence from a randomized trial showed that Take Charge improved health status at 12 months for people discharged from hospital after an acute exacerbation of COPD. The Take Charge process is not specific for stroke and we have no reason to believe that it would not be helpful for people with other conditions. This manual is very similar to the one for people with stroke. Please use the Take Charge workbook for people with conditions other than stroke. Please feed back your experience using Take Charge for people with conditions other than stroke.

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1. Introduction to the Take Charge process

The Take Charge session facilitates the process where the Person (and their support people)[1] 'Take Charge' of their life. The aim is for the Person to take on the responsibility for their own rehabilitation (ie self-rehabilitation) and the process of re-establishing themselves as a person independent of the effects of their medical condition. Previous research by our group has shown that 'Taking Charge'is something that people want, yet they feel stuck because either they haven't worked out how to do so or feel they have to do what other people tell them.

We know that many people in the first few months after a medical event (like a heart attack, hip fracture or stroke) or a new diagnosis (like cancer or dementia) can feel overwhelmed by the condition (and thoughts about the condition) itself, even if the problems caused by it aren't too severe. There is a combination of physical things ('I havetrouble doing…), psychological things ('Does this mean my life is changed forever?...) and life things ('What about my family? My job?...). Traditional rehabilitation tends to focus on the physical things with the (unsaid) message that once the physical things are better everything else will fall in to place.

Unfortunately, the physical improvement after some conditions can be slow or incomplete, and for some conditions the trajectory is gradual worsening over time (for example some people with multiple sclerosis, Parkinson Disease or dementia) rather than improvement. The emphasis on physical things may prevent the person grappling with the more important psychological and life questions. The 'Take Charge session' starts from the big life questionsand assists the person to identify and explore the main issues for that person.

People who successfully 'Take Charge' have some of the following in common:

i. They can see the big picture
ii. They can express who they are as a person
iii. They have the attitude that anything is possible
iv. They have support from someone (usually a family member)

The Take Charge intervention motivates people to tap into these resources if already present, or to try and develop them if they don't.

2. Components of the Take Charge intervention

There are 3 main components to the Take Charge intervention:

1. **Baseline assessment**.
   The Take Charge session commences with a Baseline Assessment which gives the Person a picture of how they are now. This enables them to start thinking about where they want to be in the future and how they might get there. It helps describe their ability to do things, and consider how much help they need. The aim is to help the Person use this information **to reflect** on where they are now in order **to look forward to** where they want to be (the next stage). We suggest a very short version of the assessment used in the clinical trials. Allow 5 minutes.

   The parts of the baseline assessment are: (these are reproduced at the end of this booklet)

[1] The capital P is intentional and reflects the importance and centrality of 'the Person' to the Take Charge process. Support people are assumed to be involved, or able to be involved throughout whenever 'the Person' is mentioned in this manual.

i. Frenchay Activities Index – this assesses advanced activities of daily living (13 questions)
ii. Modified Rankin scale – this assesses overall independence for help from others (1 response required)
iii. (optional) AMP-C questionnaire – this assesses the person's 'ability to Take Charge' (4 questions)

Following the Baseline Assessment introduce the next part of the intervention by saying that the strategy involves looking firstly at the big picture (of their lives) and then at specific areas that may interest them. Give them the Take Charge Workbook and tell them that it is theirs, it will not be collected, and that there are no 'right' or 'wrong' answers. I give a brief overview of the pages 'big picture' and 'specifics'.

2. **Looking at the big picture** (refer to pages 2-4 in the Take Charge Workbook)
Taking time on these three pages helps to get an idea of what is most important to the person. In this step the Person looks beyond the stroke and asks the big questions: 'Who am I?', 'Who are the important people in my life?', 'What do I want to be doing with my life in 6 months'time, in 12 months' time, and beyond that?' This allows the Person to describe **who they really are**. It gives some **context** for them to describe where they want to be (their overall hopes on the next page) and suggests that they can make this happen – by Taking Charge. Allow 15 minutes for the "big picture" step.

The "2 circles" diagram (page 2) is a way for the person to write (or say) how they see themselves. Start on the left hand side of the page. First, you ask them to write something about how they feel their medical condition has affected them in the circle on the left. (A support person or the facilitator may do the writing if desired by the Person.) Then you ask them to write something about **who they are as a person** in the bigcircle on the right. Some people will do this in terms of their job – I am a teacher, builder, caregiver or whatever. Some will do so in terms of their relationships with others – I am a wife, father, grandmother, mother. Some will focus on their special attributes – I am a kind person who helps others, I am a healthy person who likes exercise, I am a good listener. Some will focus on what they like doing – I like reading, watching movies, eating out at cafes, gardening. Your job is to give the person the opportunity to describe themselves. Their support people may wish to help. The final product can be displayed on the fridge or wall.

On page 3 the Person is asked to express their **hopes and fears**. Sometimes there is a paradox - only when the Person talks about their fears for the future do their main hopes become clear. For example, "I am worried that my grandchildren won't want me to read them stories because my speech is difficult to understand" is really another way of saying "Reading stories (and having a relationship) to my grandchildren is very important to me". You could say "It seems that your grandchildren are very important to you", which may allow positive ideas to flow. Other common fears have similar positive opposites (fear of another stroke or heart attack/wanting to do something to prevent a new stroke or heart attack, fear of needing to go into 'a home'/wanting to organise my life and support people so that I can live in my own home at least for now, fear of social isolation/wanting to generate ideas about contact with the important people in my life and making new contacts).

Page 4 provides an opportunity to visualise and describe their 'Best Day'. Drawing a picture, often described as a 'right-brain' process, can help the thinking process, sometimes described as a 'left-brain' process, to transition from understanding oneself as "a person defined by me medical condition" to "a personwho happens to have a medical condition". The person or their support people, including grandchildren for example, may draw anything under the 'My Best Day' heading. The facilitator may use prompts such as 'who with', 'where,' and 'doing what'.

(Note: expect some resistance to drawingdue to embarrassment and the belief that they "can't draw". Reassure them that this is to help **them** visualise something and to use the creative side of their brain. It can help to ask the personto close their eyes and imagine their best day and to describe it as they go. If the person wishes, a support person or the facilitator may draw some pictures, or take notes, to assist). When the picture is done say, "tell me about your picture" and listen to what they say. There is value in 'picturing' and talking about these things even if nothing is written down. The brain is stimulatedby new ideas, and we are trying to stimulate possibilities.

At the conclusion of the "big picture" activities ask the Person what stands out for them so far. You may ask them if anything has surprised them, or if they are conscious of a new awareness of a particular hope for the future. You will also have some idea of things that have challenged them, or motivated them, from the Baseline assessments, depending on how talkative they are! If they are struggling to identify what is important to them, ask them to tell you more about one of these. Perhaps say something like, "I heard you say something earlier about _____ (event coming up in the next little while) can you tell me more about that? Is that something that might fit in here (hopes for next 12 months)?")

3. **Breaking it down into do-able pieces** (refer to pages 5-11)
During the "big picture" activities the person may have become aware of a particular area they wish to start with. Tell them that the booklet pages 5-11 are designed to help them to focus on specific areas for change and to generate some ideas about how to work towards the desired changes. Ask them to choose which area they wish to spend time on first. Encourage them to decide which one would be most useful to them. Work on the first domain thoroughly; your job is to mentor them through the process **in one** area for change in this session. Allow 20-30 minutes for this part of the session. If they wish to do more than one, check with them if they have the energy to continue. Later on you may encourage them to continue further work with their support people, perhaps using other suggestions in the booklet.

Questions to ask may include, "What do you want to do in this area?", or "Let's look again at your overall hopes, aims and aspirations on page 3…. Is there something there that can help you?" or "let's look again at your best day – is there something there that can help with identifying ideas for this area?" A common occurrence is that people often want to read the examples and they can be worried that they may 'get it wrong', so it is worth reassuring them again that the booklet is for their own use there is no right and wrong. When it seems they are done, ask "Is there anything else that you think belongs on this page?" Reassure the Person that they can come back and add to it later if something occurs to them.

The focus should be on what the Person can do for themselves, with rehabilitation services and other providers regarded as a useful part of the plan. **Your job is to let the Person and their family do the talking and to come up with a Take Charge plan**; you can assist by being like a reflecting wall. You are not the problem-solver.

For example, if the Person asks, 'How I am going to improve my walking so I can manage at the supermarket?' say something like, 'what things can you think of that could help you (right now)?' The Person or their support people might suggest lots of different ways of getting round the problem (eg taxis, using a wheelchair at the supermarket pushed by one of the children or grandchildren, online ordering from the supermarket, none of which require any improvement in the person's mobility) which, **if the ideas come from them**, are more likely to be acceptable and successful. (Be aware that when the facilitator offers possible solutions like, 'You should talk to

your GP about organising more physiotherapy' the control is taken out of the hands of the Person and their family.)

It can be difficult to decide exactly which box to write things in – try not to stress about that – the important thing is that the Person has been stimulated to think about the future, and to think about smaller steps (or one step at a time) in making their way towards a future that they want.

Many people struggle with ideas around preventing stroke. The graphics in the Take Charge booklet (see page 12) are there to help them identify prevention strategies. The following health education information may also help (they may have been given this information already by their health care providers and it has been forgotten or lost in the mass of information they have received post-stroke). The risk of stroke in the first year after a stroke is 5-10%. It is possible to reduce this by up to half with control of blood pressure (the most important), increase in activity, appropriate diet, medications (particularly antiplatelet agents like aspirin and clopidogrel, lipid lowering agents like simvastatin or atorvastatin, anticoagulants like warfarin and apixaban (or similar agents) for people with atrial fibrillation), and stopping smoking. Showing where the person is now on the BMI chart, the BP and activity charts can provide them with the incentive to improve themselves.Target levels are shown on the charts (normal BMI, BP <135 systolic, <80 diastolic, activity 150 min/week ie 30 minutes on 5 days a week).

3. Handy hints to facilitate 'Taking Charge'

The overall strategy can be summed up as C.L.R.A.:

Connect with the person. Acknowledge who they really are.

Listen to what they have to say (and don't interrupt)

Reflect back to them what they have said, paraphrasing as needed

Ask if you have summed up what they want correctly and, if necessary

Ask if they can think of how they might achieve their hopes

You are not there to provide ideas – all the ideas should come from the person and their support people.

Key words:

So, I'm hearing that…*or* Let's see if I've got this right….

How important is it to you that ….

How confident do you feel that you could….

What would need to happen for you to ……

The most important message is **not to talk too much!** It is very important that the ideas come from the person and their family and not from you. Taking Charge is a process that can take time – by the end of the session there may be very little written down. That is OK. Some people will think about the issues over days, weeks and months. You are simply providing some tools to help start or reinforce that process. Youwill come across a large variety of people, family arrangements, and openness to these ideas.

Some key things to remember:

- **The aim is for the Person to Take Charge**. You are not the person 'Taking Charge' – we know that a straightforward 'problem-solving' approach after stroke is not effective and you must not try and do this, however 'helpful' you want to be.
- **Allow the Person to do most of the talking**. The best way to take control **away** from the person with stroke is to talk – it is very hard to listen and not talk, especially if the person is not talking (much). Resist the temptation! If you reach a road block – try and summarise what the person has said. Here's an example: "So you have said that you want to be able to go to the bowls club every week but you don't think you can manage that right now". Follow this with either "What do you see is the biggest problem stopping you?" or "Can you think of any way you could get to the bowls club now, even if you didn't play?" These openings may allow the person to talk and focus on smaller 'chunks' of the problem (how to get there, what I can do once I am there, coping with the embarrassment of their hemiparesis/slurred speech/walker in front of others, getting too tired etc). However, it is up to the person (and/or their family) to come up with ideas and possible solutions.
- **Do affirm their generation of ideas** for example, "It's great that you are coming up with these ideas". Avoid making value statements about the ideas themselves such as, "That is a really good idea". People, perhaps especially those on their own, will have a tendency to say what they think you want to hear. If you say 'good idea', that may stop them from either reflecting on the idea as good/bad/impractical and, more importantly, stop generating new ideas.
- **Remind them of the "big picture".** If ideas dry up, revisit the 'My Best Day' and '2 circles' drawings for ideas, go back over hopes and fears but don't apply pressure to generate ideas.

The best stimulation is them coming up with ideas. You may again say, "let's look again at your picture" or "tell me again what you value in your life" or "I wonder if what you were talking about earlier, something about music, …how could that help you with some ideas here?" If you do hear yourself saying something more directive than you would like, stop and take some slow deep breaths, remind yourself that it is their thoughts and ideas that are 'the gold we are mining for'. Relax and let the magic happen. If all that happens during the Take Charge session is the baseline assessment, handing over the Take Charge sheet and explaining how to use it and nothing is actually written down, **That is OK!** Those may be the most important elements of the intervention.

	circle one number only
Modified Rankin Score 'usual daily activities' are basic things like walking, eating, dressing, showering, toileting	0 = No symptoms or signs 1 = Symptoms and/or signs but no disability 2 = Disability but independent in usual daily activities 3 = Requires help for 1 or more daily activities but still mobile 4 = Dependent and needs help for mobility 5 = Bed bound

Frenchay activities index (write number against each item)	"Since your stroke, how often have you done the following?"
1. Preparing meals 0 = never, 1 = <1x/week, 2 = 1-2x/week, 3 = most days	
2. Washing up 0 = never, 1 = <1x/week, 2 = 1-2x/week, 3 = most days	
3. Washing clothes 0 = never, 1 = 1-2x/3 months, 2 = 3-12x/3 months, 3 = at least weekly	
4. Light housework 0 = never, 1 = 1-2x/3 months, 2 = 3-12x/3 months, 3 = at least weekly	
5. Heavy housework 0 = never, 1 = 1-2x/3 months, 2 = 3-12x/3 months, 3 = at least weekly	
6. Local shopping 0 = never, 1 = 1-2x/3 months, 2 = 3-12x/3 months, 3 = at least weekly	
7. Social occasions 0 = never, 1 = 1-2x/3 months, 2 = 3-12x/3 months, 3 = at least weekly	
8. Walking outside > 15 mins 0 = never, 1 = 1-2x/3 months, 2 = 3-12x/3 months, 3 = at least weekly	
9. Actively pursuing hobby 0 = never, 1 = 1-2x/3 months, 2 = 3-12x/3 months, 3 = at least weekly	
10. Driving car/ going on bus 0 = never, 1 = 1-2x/3 months, 2 = 3-12x/3 months, 3 = at least weekly	
11. Travel outings/ car rides 0 = never, 1 = 1-2x/6 months, 3 = 3-12x/6 months, 4 = at least 2x weekly	
12. Gardening 0 = never, 1 = light, 2 = moderate, 3 = all necessary	
13. Household/car maintenance 0 = never, 1 = light, 2 = moderate, 3 = all necessary	
14. Reading books 0 = none, 1 = one in 6 months, 2 = <1 per fortnight, 3 = >1 per fortnight	
15. Gainful work 0 = none, 1 = up to 10 hr/week, 2 = 10-30 hr/wk, 3 = >30 hr/wk	

Autonomy Mastery Purpose Connectedness (AMP-C) measure Score each component 1-4 and AMP-C 'Sum' score = sum of all components 4-16

Score	1	2	3	4	
1. I feel in control of my life	Disagree strongly	Disagree	Agree	Agree strongly	N / A
2. I have the skills to make the most ofmy life.	Disagree strongly	Disagree	Agree	Agree strongly	N / A
3. My life has a clear sense of purpose.	Disagree strongly	Disagree	Agree	Agree strongly	N / A
4. I feel connected with the importantpeople in my life.	Disagree strongly	Disagree	Agree	Agree strongly	N / A