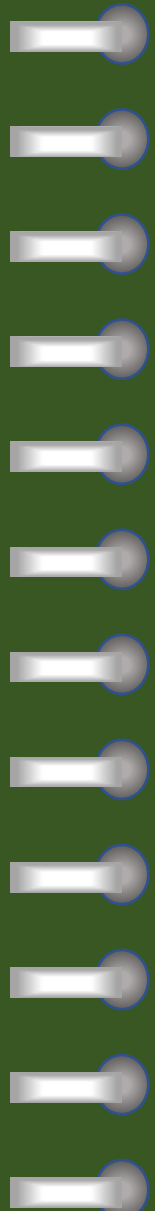


The lived experience of using a standing frame as part of a home based self-management programme: a narrative.

Jarrett L, Hendrie W, Dennett R and Freeman J



'Real stories are about actual people. True stories reflect real life situations that people encounter'

(Fairbairn, 2002)

This narrative describes the experience of individuals over the 9 month duration of the SUMS study.

We thank the people with MS who generously shared with us their stories, from which this narrative was created.

Month 1

Bob – Mantelpiece

I have just got up in the standing frame, it is so exciting. I feel comfortable and I am chuffed as not only am I standing up straight, but I am looking down into the room and out of the window to the great outdoors. It's a major plus being able to stand up because everything looks the size it always used to and I don't feel like a little tiny seven year old insignificant boy.

I have had the standing frame two weeks, it's great to stand tall. It is about five years since I stood up straight, I have used other frames but they didn't allow me to stand so upright and tall. I am over six feet in height and so this is actually the first time in a long time that I am taller than everyone in the room. I had forgotten what it is like to look down on everybody. I am almost as high as the door frame, which is quite amazing. I am smiling as it is the first time I have looked down on to the top of our mantelpiece. It is weird, I don't think many people realise that when you are in a wheelchair you are constantly looking up; looking up at people, doorframes and even looking up at your own mantelpiece.



Bob – Positioning

Month 1

For the first 3 days I felt really fatigued, my legs ached and I didn't really want to do the exercises, but I have started to lean from side to side, forwards and backwards and raising my arms, although to balance whilst exercising I tend to hold on with at least one hand! I have noticed I can get lower back ache after about 10 minutes, and sometimes in my knees too, but this usually settles fairly quickly after I sit back down.

I don't actually have a lot of sensation in my ankles and feet. I can't really feel them when I am in the frame. I get concerned about their position and whether or not they are pointing in the right direction. So I usually ask my wife, Pam, a couple of times to check that my feet are still straight and the right distance apart, because otherwise I know that I wouldn't be standing properly. Once or twice in the first week I think they were a little bit too close together, but now at the end of week 2 I can stand more comfortably and steadily with my feet apart.

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Bob – Positioning

Month 1

Being able to stand supported gives me a different kind of freedom because I don't have to cling onto anything. I can even slightly rock forward and back. It may sound strange but usually I have a total lack of confidence, I cling onto everything as I walk, but in the frame it's like a kind of freedom. Although I am strapped in and can hold on if I want to, I am able to safely move and it's really very enjoyable in a sadistic kind of way.

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Pam - Visitors

Month 1

Bob's mum visited and saw him standing she was absolutely amazed. It's a long time since she's seen him standing, they reminisced about his youth and how active he had been. It was nice but she looked kind of shocked and she had tears in her eyes.

Also, when friends come that have never seen him standing, first of all they can't believe how tall he is. I suppose when he is sitting down all the time it is difficult to tell, but they are all so impressed to see him standing.

Bob - Letting go

I have had the standing frame for 3 weeks now so the initial excitement isn't there any longer, but having said that it is very pleasurable to be standing. It gives you a sense of normality, perhaps normality isn't quite the right word, but I do feel more normal and natural even though I know I am still being held by the straps.

I was away for the weekend and I probably tired myself out a little bit, but I have tried to keep on standing as much as I can in the frame. I am still a little anxious to make sure that I am standing upright and that my shoulders aren't too stiff. I am a very tense person and most of the time they aren't relaxed but I will keep trying.

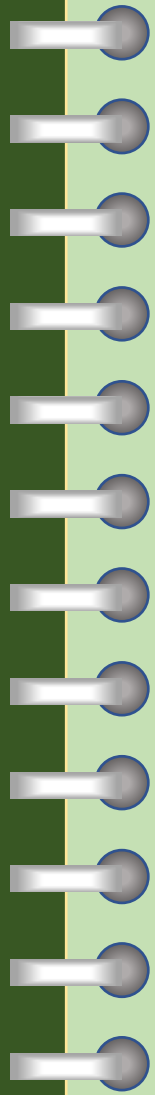
I still hold on rather a lot, but the white knuckles are lessening. At times I am definitely able to let go and put my arms up in the air above my head. When I do that I really focus on putting my weight down through my legs. I have even tried stretching my arms out to the side as well as rotating my head.

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Pam – Using the frame

Month 1

Bob had no problems getting into the frame today and he felt very secure once standing up. He said he had less aching in the lumbar region and overall felt very comfortable. He is wearing shoes today which seemed to have solved the problem with his balance. He managed to do quite a few exercises and to stand for 25 minutes, he's feeling good and it's great for me to see him like this.



Bob – MS symptoms

Month 1

I have gradually increased the time in the frame. To start with I was standing for about 10 to 15 minutes and now I regularly stand for thirty minutes. I can truthfully say that when I stand for that length of time I feel I am exercising my muscles. My calves and thighs ache but pleasantly as if my body is saying to me; 'Hello you're using muscles that you're not used to using.'

I think I must be standing more upright as my stomach muscles feel different. My balance is improving and I feel more confident about doing things around the house. For instance I have managed to get up from the toilet and pull up my trousers without feeling I have to hold onto anything, so little goals like that I am achieving.

I'm finding less problems with leg spasms in the morning, although some days my legs have been quite stiff and weak, but my MS symptoms often fluctuate and its nothing I haven't had before. Some days I feel more fatigued than others but I guess that is to be expected too, it's just the ups and downs of MS.

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Bob - Surfing

Month 1

I was brought up in Cornwall and between the ages of 13 and 20, my friends and I were always surfing, we surfed in the summer and in the winter, it's all we did. The reason I am saying this is, when I am in the standing frame if I let go of the table or the side arms and don't need to hold onto balance I can put my hands down by my side, lean back, relax and it feels a little bit like surfing. I can imagine myself standing on the surfboard with my arms down by my side and I just move my body around a little bit in the straps as if I'm moving the surf board. Maybe it seems silly but it's a good feeling and I feel relaxed. I am enjoying it tremendously.



Bob – Physiotherapy support

Month 1

I was feeling a bit anxious about how much exercise I should be doing, but then my physiotherapist came and saw me standing in the frame and was very encouraging about how I was doing. It was great to get such positive feedback. She is keeping me on track, showing me the best way to do the different exercises. She suggested that if I try to gently and very slightly bend my knees when I am standing this will help me to stop hyperextending my knees. I now do this and it gives me confidence that I am standing correctly. I also can tell by looking at myself, where I have got the frame positioned I can see my reflection in a glass door ahead. I can check whether I am upright and reposition myself as needs be, but I cannot see my feet, which is why I get Pam to check. I keep reminding myself to keep my shoulders down, and sometimes I tense my shoulders so that I can then release them and tell the difference. The physiotherapist also suggested a warm up session, when I do this it helps me with the exercises.

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Bob – The feeling of exercise

Month 1

My muscles feel worked, but not over worked and not painful. I do feel fatigued but overall I feel as if I am improving. Certainly my leg muscles notice they've been used which is good and I'm doing other exercises like sitting on the chair and standing up without any support and then sitting down again gently.

If I am honest I thought I would progress quickly through the exercises but I now realise they are not that easy. I feel impatient because I want to see a difference as soon as possible although my physiotherapist did say it is probably going to be a number of months, if at all, and whilst I am well aware of that I still want change to happen quickly, like tomorrow! All I can do is continue with my standing, 'surfing' and trying to put as much weight as I can through my leg muscles.

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Pam – Using the frame

Month 1

We are getting more familiar with the frame, using it is getting easier. When Bob first stood he was constantly falling forwards and using his arms to support his body, but I think his balance has improved and he is not putting so much weight through his arms.

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Bob – Good day

Month 1

I am feeling pretty good, yet nothing has really changed other than doing some standing. I feel I have regained a chunk of my youth, as though I want to go and do stuff. For instance today I have been out in my car to the local supermarket, got in the wheelchair, whizzed in and got food for our evening meal and it feels good. I have actually enjoyed being in the frame, it really has given me a sense of liberation.

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Bob - Sadness

Month 1

I haven't managed to stand as much this week as a good friend unexpectedly passed away. I attended his funeral this week and just feel sad. I must admit I have been sitting around at home rather than doing any extra exercise and it's not good really because if I don't do stuff I get worse.

I enjoy the freedom of being in the frame, letting go for periods of time and turning my head from side to side, twisting my body to the left and to the right. When I put my hands up in the air I try and make sure my shoulders aren't tense. I don't feel any ill effects in my ankles or my legs at all and I don't feel any great need to sit down after I come out of the frame either. So my lethargy is nothing to do with the frame, I think it is purely down to my mood and it's something that I just need to overcome. I will bounce back, but it's just been a bit of a shock my friend dying so suddenly, his illness was short, three or four months and now he has gone.

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Bob - My friend Dan

Month 2

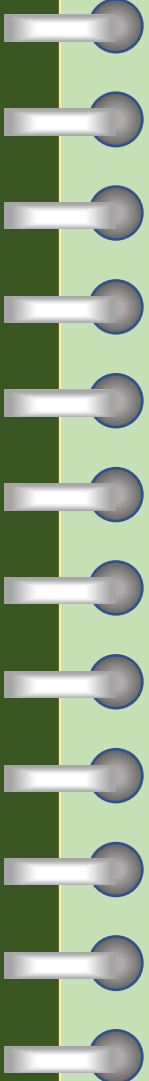
My mood is starting to pick up. I was chatting to Dan a friend of mine with MS, he is also on the SUMS trial but he is able to walk further than me and has different goals. He hopes to walk his daughter down the aisle in a few months' time. I hope he can as it means so much to him. He is quite a character, he loves country pursuits. He has just managed to attend a pheasant shoot. He rode a quad bike over the uneven ground, but then he stood to shoot by resting his bottom on the quad bike frame. He said he hasn't been able to do this for ages. He feels the standing frame has really helped him with this. He managed to swing through and shoot the last bird of the day and was chuffed.

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Bob - Stiffness

Month 2

My standing is going quite well overall. My stomach muscles are improving as I feel able to sit up on my own more easily. I don't know though if I have really noticed any improvement in my legs. They can feel quite stiff immediately after I get out of the frame but that soon passes. Although, at night and I am not sure whether this has anything to do with it, my legs can be very stiff. I used to be able to roll over by myself. It was a bit of an effort, I pushed and shoved and I sort of flopped myself over onto my other side. Now I am finding that I am more tired and stiff and sometimes I have to wake Pam up to help me turn over in bed. I don't know whether that is just a progression of my MS or whether I am getting tired from standing regularly, hopefully if I keep going with the standing frame, this will improve.

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Bob - Knowing if you're standing straight

Month 2

It may sound strange but without seeing my reflection it is very difficult to know if I am standing straight, I get strange sensations that I am not straight.

I don't always have the time or energy to stand in the frame in the morning, so I've been doing it in the afternoon, although that is not always ideal. In the early afternoon on a bad day I can get quite tired, so sometimes I have a quick sleep before I stand, and that seems to help.

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Pam – Ongoing use of the frame

Month 2

Bob used the standing frame again today. He managed 30 minutes, which isn't bad considering he did it yesterday as well. So we are quite pleased. We have got the straps sorted now. They are all in the right place for him, so we are getting a lot quicker using it.

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Bob - Hot weather

Month 2

The weather has been quite hot this week and I have been suffering from fatigue and general lethargy. I have been standing but I haven't been doing a lot of walking. I actually feel quite low, the hot weather makes everything harder. I tend to just sit and read and not do much exercise, but on a positive note I did go to my exercise class today. I am glad I did as it lifted my mood. The physio helper was very impressed with me. I was on a sort of perching stool on a vibro gym and she was encouraging me to stand up from the perching stool. Although I had my hands on a bar she said "try to stand using just your leg muscles, try not to use your arms". I managed to do it three times in a row. I did it and she was really amazed as they expected me to use my arms and I was doing it just using my legs. I am really pleased with myself, and wanted to record this as obviously I had strength today.

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Bob – Being a dad and a husband

Month 2

The novelty of the frame has worn off, it is not as exciting as it was but I am still enjoying it tremendously. This morning I was standing whilst my daughter was practising her violin. It was good doing these things together in the same room. I had to use my arms to balance today, I am still having to do that some of the time, but this meant I couldn't put my fingers in my ears at the appropriate moments! Only joking, it was great fun to stand and share this with her.

It is really nice to stand and talk to people as you are standing. My wife is sometimes in the kitchen and I'm in the frame in the dining room but we can see each other and chat.

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Bob - Raised temperature

Month 2

I have had a few days off standing, I caught a bad cold and as always it affects me quite badly, especially when I have a high temperature. I couldn't lift my arms, or walk and needed help to do things. It is so frustrating when it happens and the fatigue is a real challenge. Even getting out of bed and having a shower leaves me exhausted. I am back to standing today, it is all back to normal and I am glad, I quite missed it.

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Bob – Scrunched up

Month 2

Without standing I am sitting all day in a wheelchair or on a sofa. I am constantly in a seated position, a curved bent position. All my organs are scrunched up inside, the standing frame gives me quite a nice feeling of being stretched out. Although you can stretch out in bed, it's not the same.

It's very nice to be standing again and stretching my muscles. Although I don't think the standing frame has helped to improve most of my MS symptoms, it is fantastic to stretch my muscles and my body and it has a positive effect on my mood, but the down side is I struggle to see much impact on my MS.

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Bob - Reflection

Month 2

Maybe if I reflect more carefully my core strength is improving and also my ability to twist and turn when I do the exercises. Maybe my legs are a bit stronger too. I started off with 10 exercises at a time; I'm now up to 30 so that is clear improvement. I'm standing with a bit more ease in the frame and last week I was able to stand beside somebody and have a conversation, although I still had my crutches it was easier, so maybe I am seeing changes they are just not always obvious.

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Bob - Wedding

Month 3

I have just heard from Dan, I am so pleased for him, he accomplished his mission. He managed to walk his daughter down the aisle. He was so thankful for the help from the physiotherapist and the frame. He is pretty shattered now though, typical of MS symptoms, but as he said "worth it".

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Bob - Update

Month 3

I am doing half an hour a day. I am not sure if that is good or bad, but I was originally told to aim for this length of time every other day, I wanted to work hard in the hope the more I do, the quicker it will have an effect but, I know it may not.

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Bob - Exercises

Month 3

I am adapting how I do the arm exercises, I find it hard to keep both out in front of me so I tend to alternate or do the exercises in a different order to what the information sheet shows. Slowly I am finding that the muscles in my legs are responding a little bit better on a day to day basis while I'm walking around. They feel stronger.

I make sure that I turn my head and body a lot and I enjoy the sensation of actually feeling upright because I do walk with a stoop when I walk with my rollator. When I am first out of the frame, I certainly find it easier, at least for a little while, but it doesn't last sadly, but for a little while I find that I am walking far more upright.

Oddly, I can still have the sensation when I come out of the frame that the back strap is still around my bottom. I can feel it there for a few seconds after I am out of the frame.

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Pam – Two hands

Month 3

The other day without realising it Bob used two salad forks to serve his salad he didn't need to hold on and used both hands simultaneously. He can also now get his jumper on and off without help and that is also a big plus point.

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Bob - The unpredictability of MS

Month 3

Well after being very positive, I went to an exercise class yesterday and I was unable to do much at all. I was just completely fatigued. So, I did come away feeling a little despondent I must admit. Although in the evening I felt a little better and managed to stand. I think it is just the nature of my illness, it fluctuates, I know only too well that you can have good or bad days. I know I shouldn't get despondent but I still do, even after all these years living with MS.

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Bob - Mouth ulcers

Month 3

I haven't been feeling too well over the last few days I have had some mouth ulcers that would not heal and so I've needed antibiotics. Any infection affects my MS symptoms and hence abilities so my standing and walking have not been as good which probably explains why taking part in the exercise class yesterday was a struggle.

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Bob – Holiday

Month 4

We went away for a week and I was concerned about getting back into my standing but it was ok. I thought I had lost motivation but I had no problems starting again and stood for almost 30 minutes.

Friends have noticed I'm standing up straighter. I'm walking a little quicker and my strides are a little bit longer.

Bob – Still trying to improve

I was hoping to have increased the length of time I stand. Occasionally I've done a bit more, but usually by half an hour my legs have had enough. So I haven't really progressed much in terms of how long I'm standing for. I stand about four times a week now, every day was too much. My symptoms have been quite up and down, it's very hard to know whether the frame is contributing to this or whether it's just the MS. I do think my back and core muscles are stronger. I can sit up better on my own, so that's a good thing.

I haven't been sleeping very well recently which I don't think helps with my symptoms. The day after a bad night's sleep can be really hard, but I usually manage to do my stand. Sometimes I struggle to make the 30 minutes and other times I'm fine doing that length of time. I continue with the exercises and I've now got a small dumbbell weight which I lift with my arms. I started off doing maybe 15 or 20 lifts but I now can do up to 40 with each arm. I find that my arms get tired after the thirty minutes. So that's the limiting factor. Not my legs, but my arms.

Today is a nice sunny day, looking out to the garden is wonderful, standing up watching the birds on the feeders.

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Pam - Spasms

Month 4

Bob had a slight spasm as we were preparing him to stand today; first time that has happened. We let it settle and he managed to pull himself up very easily. He managed all of his exercises and is now using a 2 kg weight. He finds it easier to lift it with his right arm.

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Bob – Dan

Month 4

Just had a very excited Dan on the phone he managed to stand when helping out in the bar at his recent pheasant shoot for a total of an hour, three 20 minute slots. He feels the standing frame has really helped his posture and arms in particular. Its great news as he had a fall recently and hurt his hip, which he was worried about. Although he did admit his hip can be uncomfortable after a busy day.

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Bob – Visiting others

Month 5

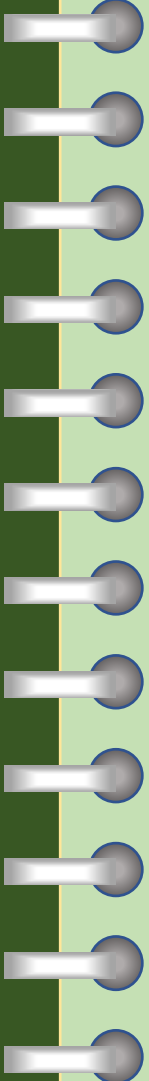
I went to lunch at a friend's house, she has a narrow hallway and I always find it difficult to take my crutches or my rollator. However as I've had no falls since I've been using the standing frame and feel more confident with my balance, I decided to walk in using my wife's arm on one side and my crutch on the other. To walk to the toilet, I used my crutch and leaned on furniture. It was great, I managed fine.

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Bob – Pushing the time

Month 5

For the last few days I have managed to stand for forty five minutes. I noticed that the thirty minutes was becoming easier, more comfortable. I decided to up it a bit to forty five minutes and now I am finding that quite hard. My muscles are aching and at night in bed I am quite stiff. But I am hoping that if I can continue with the forty five minutes, it will get easier.

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Bob - 45 to 30

Month 5

I have been trying to do four days of standing for 45 minutes then having one day off. However, I was tired and stiff and when I went to bed I couldn't roll over. I have reverted to thirty minutes. That extra fifteen minutes surprisingly took it out of me quite a lot. I don't know if that is fatigue from using the standing frame or just fatigue kicking in generally with my secondary progressive MS. I guess my MS is progressive, so maybe it is progressing. I don't know, it is hard to tell.

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Bob - Holiday

Month 5

We have had two weeks holiday. I managed to keep standing by using the rail around the balcony of our apartment. I used a cushion to support my knees and a chair behind me. It worked!

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Pam - Exploring

Month 5

When we were on holiday a couple wanted to take us out for the day, normally he would have declined because of worries around not managing strange places but he was completely up for it. The hire car was so small we had to take the wheels off his chair and he had the frame on his knee! But it was fine, he went nearly everywhere the rest of us went; going into churches and even onto the beach with our help. His confidence has really improved.

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Bob – Back at home

Month 5

Doing my frame today I was quite good. I managed to do lots of exercises pretty much for the whole 30 minutes which is unusual. So it's very hard for me to know what I'm going to be like until I actually get in the frame. Sometimes I'm good, sometimes I'm bad, but today was a good day.

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Bob - Warm weather again

Month 6

It has been really hot for a couple of days and quite humid and I've been really struggling with weakness and fatigue. I've not been able to do my standing frame as usual today.

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Bob – Next day

Month 6

It is still quite hot, but I'm not quite so bad and I managed to do the standing frame today for 30 minutes, but it was quite a struggle. Had to sort of hold myself up, by keeping my hands on the table in front, which I don't normally have to do. But I just about managed it and felt pleased that I tried.

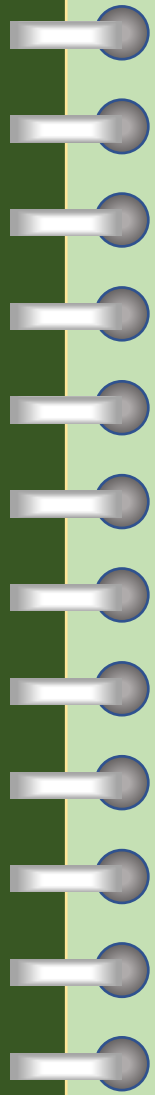
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Pam - Warm weather

Month 6

Bob has done his standing today but only managed to do 15 minutes which he was really disappointed with, but I think the hot weather is affecting how he's feeling.

On the whole his stand is going really well. It's just remembering to fit the stands into our daily routine. We started off well but seemed to have lost it a bit this week, but hopefully now the weather is cooling, things might get easier.

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Bob – Maybe standing is doing more than I realise

Month 6

I have two examples firstly, my next door neighbour who lives with Parkinson's, fell over coming down our drive. We rushed to help her, another neighbour passed her 2 year old son to me to hold whilst she helped. I did it, I managed to hold the boy for a good five minutes; I couldn't have done that pre frame.

Then last night our house fire alarm went off, well it didn't go off exactly, it was the low battery warning; it started bleeping at 3 o'clock in the morning! With support from Pam I managed to stand on the bottom rung of the steps to reach and disconnect it. I am sure without the standing and exercises I would not have had the strength or balance to do it and it would have been bleeping all night.

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Bob – Friends memorial

Month 7

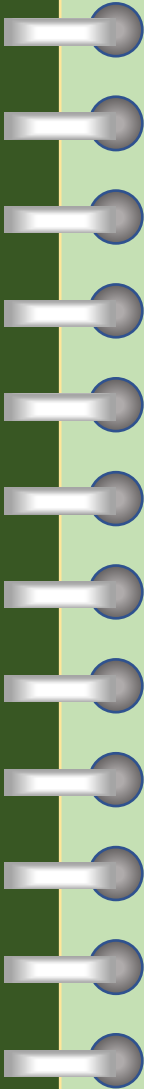
I went to my friend's memorial service, they had quite a few hymns and I managed to stand for them. There were periods after the service where I was standing and talking to people, I managed because of the exercises I have been doing with the frame I am sure. I am shattered today though.

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Pam - Struggle

Month 7

Bob struggled a little bit getting into the standing position today. He was not quite as stable as he has been and he found it difficult to raise his hands and stay standing, he kept falling forwards. He only lasted 20 minutes today, he was very tired and needed to sit down. That said, standing in the frame does improve his posture after he has used it.

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Bob - Dan

Month 7

Dan's really enjoying the standing frame. He has managed to go to the pub with his son, and for the first time in ages he was able to stand at the bar to have his pint!

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Bob - Massage

Month 8

I had a massage yesterday and it helps considerably. I've spent quite a bit of time over the last week on my feet and I'm not aching quite as much. The last week has been virtually pain free and I'm quite happy with how things are going. Yesterday when I was standing up, my daughter came in and gave me a hug, it's the first time in nine years that has happened in standing, it felt really good.

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Pam - Dressing

Month 8

Sometimes we use the frame to help Bob get dressed in the morning. You know, he wheels his wheelchair commode up to it and stands leaning over the table without the straps, he can then support himself and pull up his pants and trousers. It is really fantastic.

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Bob – Summing up

Month 9

Over the last few weeks my back's been aching and I have gone into spasm a few times but basically I would say, overall, that the standing frame has been of benefit. It has helped me mentally and physically. I am certainly happier to stand than when I started, my knees and back don't ache quite as much. I feel stronger and I know that it's strengthened my middle. In some ways I feel it has got to help, just by the fact my muscles and all my internal organs fall into the right position for the short time I am standing, as opposed to being crunched up in my wheelchair.

I would have liked more feedback from the research team and physios just to come and check how I was doing and to provide encouragement. There have been times when I have felt quite isolated and wondering why I was doing it. Although slowly I have noticed that I am able to do more things around the house, my walking isn't particularly any better but certainly doing projects and just day to day things around the house has improved and I would say that was probably to do with the standing frame equipment and also my improved mental state.

A decorative spiral binding on the left side of the page, consisting of a series of white rings connected by a dark line.

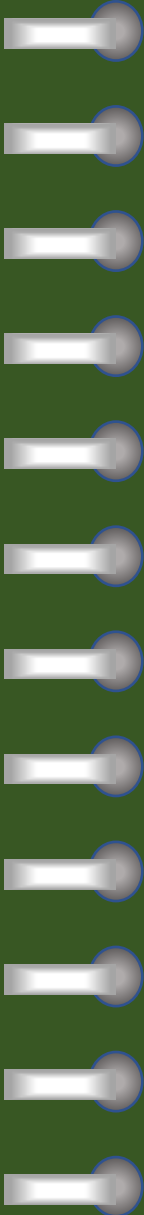
Pam - Future

Month 9

We definitely want to keep the frame. Bob loves it!

It has made such a difference. Not just physically but he is so much more positive about things. He has always hated days when he didn't do anything but now every day he feels he has done 'something' because he can use the frame.

Luckily it fits easily in the house so he can either watch the garden or the telly. It doesn't feel like a chore. He stands nearly every other day, and nearly always now for about forty five minutes. He throws balls into a box and he can now catch them when I throw them back. I've noticed that he is hardly ever constipated now and he doesn't seem to pass urine so much in the night either. He has more strength and there have been no falls transferring into our new car. The knock on effect is that this all makes my life easier, as well as his. Plus, there is one more thing; he's much more interested in nocturnal activity!



Construction of this narrative was undertaken by the primary author (LJ), a specialist MS nurse, after reading and re-reading the texts. It was reviewed for coherence and relevance by members of the research team (JF, WH, RD), who are all MS Specialist Physiotherapists. The reading of the texts was influenced by their knowledge and experience of MS and their roles as MS specialists. In particular how MS symptoms can impact on a person's daily life and function stood out in the stories and were highlighted in the narrative.

Further explanation about the methodology used is available on:
<https://www.plymouth.ac.uk/research/sums>

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The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.