

# Living Life on Wheels

ALAN BUTLER, VAUCLUSE GARDENS

SEPTEMBER 2021

Daniella Polita asked me to jot down some experiences. My main message is: **hope for the best**, but, especially with big items like remodelling a bathroom or buying a new house, plan for the worst!

The details of my medical condition are hardly relevant here, but briefly, I suffer from a hereditary, progressive neural disorder that affects coordination and balance. So, I started in my early 60s needing a walking stick to maintain balance (but I could walk a couple of km with that and could go up and down stairs using the handrail). I progressed to using a scooter for substantial distances but being able to get off the scooter and walk with a stick (e.g., into shops which had a stair or two at the entrance).



At that stage, I still did all the shopping (riding the scooter around the supermarket) and some cooking. In the next phase, my arms grew weaker and poorly coordinated ... this meant that I couldn't any longer haul myself upstairs, nor could I safely lift things off the supermarket shelves.

We lived in a three storey unit, so we bought a stair lift, an excellent machine which went round corners so it would carry me up all three levels or let me off at intermediate levels. But it meant having a walking frame waiting at each level – and being able to walk with the frame. At the ground floor, I was still able to get off the stair lift and walk a few steps outside to get on my scooter. But the writing was on the wall!

I am now wheelchair-bound and can only go a few steps with a walking frame, but we now live in a single level unit and almost the entire village provides level access and proper wheelchair ramps.

There are still tricks (e.g., dictation in place of typing) that enable me to enjoy life. So, what tips can I assemble from all this?

## MAJOR TIP: PREPARE FOR THE INEVITABLE WHILE IT'S STILL EASY

- ❖ Living in denial will get you a long way, but it's ultimately a dumb idea! If you're adopting a solution that will only work for a short while, then don't spend too much on it.
- ❖ As a general rule, for "normal" people, not only people with neurological illnesses, it makes sense to anticipate that things are going to get worse. This sounds gloomy, but is realistic ... even if you're young, ask yourself how you would manage if you broke a leg. If you're older, and finding it difficult to climb the stairs, then you can bet it's going to become more difficult, and life will suddenly become much more pleasant if you take the plunge and move to a more accessible house.
- ❖ If you're changing houses for reasons other than immobility, take the opportunity to plan for the almost-inevitable trouble ahead. This may mean going for a single level. It may mean installing a lift, or at least making provision to install one later. It may mean planning so that, even though the house may have two or more levels, it is possible to live on a single level (make sure there is a bedroom and a bathroom on the same level as the kitchen, for example).
- ❖ So, what's needed is a tricky balance between soldiering on as long as you can (admirable) and at the same time planning to make things easier if something goes wrong (sensible). Loss of mobility isn't certain, but it's quite likely.



## MINOR TIP: WALKING AIDS

- ❖ The simplest of these is a walking stick. I have been surprised by the number of people of advanced age and quite poor coordination who still refuse to use one. There are many designs. I carried a folding aluminium one on interstate business trips for some years.
- ❖ The next level is a walking frame. These days, most of these are wheeled. They really do help, up to quite a serious level of uncoordination. Again, some people refuse to use one – I think this is unwise.
- ❖ Don't worry about the embarrassment effect! There are a lot of models, so be selective: I have two, and have found that this design is good.



- ❖ This kind of design is more elegant, folds sideways instead of vertically, which is better for loading in some kinds of cars (by an able-bodied helper) but is rather less stable because of the flexible seat and back. The one I have is also wider, and a little longer, which makes it more difficult to manoeuvre around the house.



- ❖ There are numerous other designs, some with bigger wheels, which is an advantage if you plan to travel on uneven ground (eg. normal city footpaths! Some people do walk serious distances using walking frames). Try before you buy!
- ❖ A final, important point: keep your walking frame well adjusted – eg. make sure it is the right height, and don't let the brakes get too loose or too tight.
- ❖ The next step beyond walking frames is scooters and wheelchairs. I must say, I'm glad I am disabled now and not 30 years earlier, because the variety and ingenuity of the devices now available is amazing. But I won't go any further into this topic, because the decisions are so dependent on the particular person's needs.

#### MINOR TIP: RAMPS

- ❖ Suppose you live in an accessible house and use a wheeled mobility aid.
- ❖ It takes very little to stop a wheelchair or walker – most doors have a lip which is too high (1.5 cm or more is a barrier). There's no need to put up with these! Find a good source of ramps of varied sizes even if your house is "level".
- ❖ We carry a portable, folding aluminium wheelchair ramp when visiting friends. People often say they have level access, not realising that they have one step!

#### MINOR TIP: LEVEL ACCESS

- ❖ Shower alcoves are a trap – again, people often think they have level access when in fact there is a lip a few centimetres high, which able-bodied people hardly notice; but older people, even if not ill or disabled, will eventually find it dangerous to step over that little lip – and it'll stop a wheeled shower chair in its tracks!
- ❖ If you're having bathroom modifications done then go to the trouble of getting truly level access installed while you're about it. But if not, get a rubber ramp.

#### MINOR TIP: GADGETS

- ❖ There are lots of devices on the market to help you with problems of mobility or dexterity. Some of them really do help, but it depends on the fine detail of your particular problem. So, caveat emptor. Here are a few of my own findings:
- ❖ Fat-handled cutlery can help, but the ones I've been able to find are disgracefully expensive and poorly made – eventually the handles fall apart in use. You can do much better by taking ordinary cutlery and adding some insulation tubing (from a hardware shop or plumbers' supplier) to fatten the handle. We also have some children's cutlery, with thick handles, which works pretty well for me.
- ❖ I have tried various sophisticated tools designed to help you reach and grip things, such as jars on high shelves, or little items you've dropped on the floor. Some of them work for people with good manipulative ability, but none of them work for me. A pair of long BBQ tongs is as good or better, and cheaper!
- ❖ In short, figure out what works for you. A simple solution may be best, and cheapest. It's pretty normal to take a catalogue from some supplier of mobility aids and browse through it to see what might help. That's a good idea, but it might lead to buying a lot of stuff that doesn't help. I also advocate a different approach. That is, identify the nature of the problem first, try to invent solutions

that will work for you (this means 1. invent the solution – plenty of people will help you do that, then 2. quietly think through the whole operation of that solution in your particular case – take your time, you won't think of every aspect right away – no-one else, except a really perceptive OT, will do step 2! And then go looking at catalogues and websites to see if someone is already marketing your particular solution. If they are, great! If not, consider getting it made locally.

