

Me, My Wheelchair and Direct Action

by Katy Turquoise

Being an activist is a challenge at the best of times. We need to be prepared for any number of eventualities. Childcare needs, age and disability can make it impossible for us to be involved at all. As a Turning the Tide Resource Person with a debilitating illness, I thought I'd share some thoughts on problems I've encountered trying to protest in my wheelchair. Some of my thoughts will be transferable for people with other disabilities but I don't pretend to make this universally representative.

First, some background: in early September 2001, I received a phone call from Kiri, trying to recruit me to Turning the Tide. I'd had four years of living with ME and Fibromyalgia, curled up with constant pain, unable to walk 50 yards. I hadn't been on an action for years and wasn't sure I could do much. Kiri was sure I had something to offer. I'd had a lifelong commitment to NVDA; a criteria for new Resource People. As for current opportunities for protest, there's a day of action at the DSEI arms fair in Docklands next week. Perhaps I could try that?

I'd lost a lot of confidence and it was an intimidating prospect, but I was motivated so I went along. Since then, I've attended several local anti-war demos and the big mass rally in London in February 2003. None have been easy. It is unbelievably exhausting to stay alert, outgoing and aware for more than an hour at a time, and I'm better off than many. But my disability means I have to drag a lot of other people into helping me and given that that takes resources away from other places, I'm compelled to question how worthwhile it is.

Here are some of the things I've learnt to take into account before I leave the house for an action, and examples of how well or badly I've achieved it.

Planning

DSEI arms fair 2001: Flyers give meeting points and some idea of what might happen but by necessity give little information of anticipated outcomes. I considered getting in touch with the organisers in advance but they couldn't have helped me much, as thinking on your feet & going with change is so essential at a demo. That never mattered before but in the wheelchair the uncertainty is frightening. Will I get left behind or separated from my support people? How would I cope without them? What if it all kicks off and someone gets injured or arrested? I'm surrounded by rows of people, hedged in at hip level, can't see a thing. Suddenly the police push from behind. We are being tightly cordoned together. There is a route planned but the police have other ideas and there's chaos and confusion as the group try to go one way and the police try to push us in another direction.

Mass rally, London 2003: I plan to meet up with Alison who is willing to walk the route with me. Coming from different places, we should start from different places but Alison is willing to cross London to meet me. When I get to Brighton train station there are thousands of people pressing towards the platform and I suddenly realised that the scale of this demo is going to be unprecedented. The likelihood of my meeting Alison is next to none. We've been in contact throughout the morning but I'm getting worried and feeling very much alone in this enormous crowd. Luckily I meet some friends and their baby on the platform and they agree to stay with me so I call Alison and she's glad to stay with her group. We only get halfway round the route before my wheelchair batteries start running out and we have to make a dash for Victoria where my friends are, thankfully, able to get me home safely. So, I can make as many plans as I want but in the end they are more than likely to go awry. Sometimes it's okay, sometimes not. If I hadn't met my friends at the station my chances of keeping safe that day would have been faint.

Support People: This is the most essential thing and I don't seem to be good at recruiting helpers. At the local demos last year I roped a friend in to walk the routes with me. That worked well, being on home turf and safe enough in my environment that I could be fairly independent if we got separated. I made new friends. When my batteries ran out I was fairly near home so it wasn't hard to find help. There was fun to be had too - I was able to give lifts to tired children and met another wheelchair user, the only one so far. It seems we're few and far between.

But for DSEI I wasn't able to find anyone who was going. I took a friend's daughter with me and planned to meet up with Kiri, again coming from somewhere else. I learned the hard way that it's not fair to ask a teenager to push a manual wheelchair for miles! After lots of mobile phone calls we eventually caught up with Kiri, Chris and Ruth and I met lots of people I hadn't seen in years. Some of them were able to push a little way but the majority of the responsibility was still on Georgia and Kiri's shoulders. Georgia was exhausted from her earlier pushing and Kiri had to get home to pick the kids up from school. So I was relying on too few people who didn't have quite enough resources to support me as much as I needed.

And for the mass rally in London I rang around everybody I knew throughout the country, all of whom were going but already committed elsewhere. I was unable to find *anybody* willing to make the journey and stay with me throughout the route. This had never mattered before as I had access to tube stations and would be bound to meet up with some of them. It served to remind me of my increasing vulnerability and decreasing independence.

I've learnt that if I'm to go on a demo I need to be with at least two strong individuals who can commit to staying with me throughout the event. What worries me most is that it feels as though I'm taking their energy away from where it is most needed, just to help me feel I'm doing something. This doesn't feel like a justifiable desire.

Energy Management & Communication: This is a problem in most disabilities. People with hearing impairment, for example, are likely to find it difficult to communicate in a noisy environment. Noise is exhausting. It can be especially hard if the disability is invisible or its extent is not immediately obvious to observers. Many disabilities are likely to involve a degree of energy management as living with illness is inevitably tiring. For me, it is particularly helpful for my support people to watch for signs of flagging energy as I often don't notice it until too late, struggling on regardless.

Police and Security

DSEI 2001: the police are squeezing us tight again. I apply my brakes, trying not to squash the people in front of me, already bruised by my footplates. But Kiri, pushing me, is bent over me by the crush and people on all sides are falling over me or getting their feet run over. It's a truly hairy moment. Then the police bash Kiri on the head, grab hold of my handles & drag me out of the group. I cannot wriggle out of their grasp, there's nothing to lock on to; they have chosen to undermine the little power I have. I could get out of the chair but then they might confiscate it, assuming it's a ploy. I might not see it again and be stuck on my own; exhausted, in pain and unable to move far. At last the press eases and we are moved on up the road. The coppers who dragged me out have moved on and forgotten me so Kiri and Georgia are able to rescue me and we rejoin the main group.

This was the most aggressive of the police actions I've encountered since then. It was frightening and demoralising. They really did render me powerless; there was nothing I could do, despite being friendly with them. Their excuse for manhandling me was "It's for your own safety." But they knocked me about so much I hurt a whole lot more than I did before. It was pathetic excuse and they'd obviously picked me out before the crush started. I was an easy victim for them. Prejudice? You decide.

Transport: Many train stations are still inaccessible, you can't use the underground in a wheelchair, it's impossible to get an electric wheelchair into a coach and driving is detrimental to energy and the environment... oh, and wheelchair battery life is unpredictable. It took 4½ hours just to drive from Brighton to Docklands; then we had to wander around for an hour looking for the group. It takes serious determination and energy to even get there in the first place!

At my RP's induction weekend I raised these problems and we spent half an hour or more discussing ways that a wheelchair-user might be useful in a variety of situations. The idea of locking the wheelchair on was an encouraging one -- I could cause all sorts of trouble doing that (!) and it invigorated me to think that they were situations where I might be useful. But subsequent experience suggests that to do anything really useful I would need a highly motivated affinity group, aware of all my abilities & limitations, absolutely dedicated to achieving a targeted outcome for which me and my

wheelchair would be especially useful, fully committed to sticking with me throughout.

To conclude: what I do get out of maintaining my activism is social interaction with friends old and new. Sometimes I have fun and there is certainly a sense of at least having tried to participate, which can be euphoric. But these are side effects, not contributing to the common good. I'm not confident that in my state of health I will ever be able to manage a targeted action. Mass demos are easier because the risk of arrest is so much smaller and I know I won't let colleagues down. I can be one amongst many; my responsibilities are fewer and I need only be accountable to the people I'm with (if any!). If I ever do manage a small action, there may be a sequel to this article. Watch this space...

A few ideas for those working with wheelers:

- Be considerate but not patronising. Attempt to enable your colleague as far as possible.
- Make sure you know how best to help them and how independent they want to be. This will be different for everybody so don't assume anything.
- Keep in close contact at all times. Stay close at mass demos. Plan routes in advance. Always keep safety in mind, look out for exit possibilities; you will have a better viewpoint than the wheelchair user.
- Keep an eye open for any hazards your friend may have missed. Watch for signs of tiredness. What indicates an oncoming fit or attack? How physically strong are they? Be prepared and know how to deal with the symptoms, if any, of the disability.
- When pushing a wheelchair, remember that your friend's feet stick out further than you can see. Leave at least a foot ahead of their knees to avoid knocking other people's ankles.
- Learnt how to operate the wheelchair (electric or manual) before the action. Find out how to switch an electric wheelchair to manually case of battery failure. Learn things like how to climb a kerb when pushing, which kinds of pavements are least painful to traverse (e.g. try to avoid cobbles!)
- Make a backup plan in case of arrest, yours or theirs. Are you willing to be their spokesperson and go with them to the station? Who will help your friend if you are the one arrested?

Points for any other wheelers out there:

- When working on an action, be clear about your needs and abilities with the group. Make sure they know in advance what you can and can't do and what you are willing or unwilling to attempt... here's a challenge: If you're willing to get your kit off AND lock your chair on to something, you could really confuse the cops!
- Make backup plans and be sure you're prepared for all eventualities.
- Pack plenty of medication and/or equipment you need in case of arrest, or make use of the police doctor at the station. (If you use cannabis for

pain relief, you are now allowed to carry small quantities without fear of prosecution.) Make sure that the custody officer is aware of the nature of your disability. Bang the message home if you have to. Keep notes of any ignorant, abusive or neglectful behaviour. Evidence of all this will help if you later go to trial, especially in cases of wrongful arrest.

- I find it helpful to carry a small card printed with a short list of do's and don'ts in case I'm too tired or the pain is too great to communicate at any point.
- Accept help when it's offered, don't waste your own energy if someone else has enough to share!
- As far as I have been able to work out, the Disabled Activists Network's web site is now defunct. I don't know of any other groups who support disabled activists so if you have any ideas it would be great if you could feed them back.

(N.B. these points were written in a state of profound fatigue, therefore I cannot pretend that they are in any way exhaustive. If anyone has further ideas or advice, I for one would very much welcome it. Please do feed them back via the Turning the Tide office.)