



NEW WRITING

An Alphabet of Helpful Hints:

For new practitioners offering family-centred support to children with disabilities / special needs

By Peter Limbrick

This is a regular feature in IQJ. The alphabet covers issues which have arisen repeatedly in my consultancy and training work over the last 12 years. The suggestions humbly offered here come from my experience as a sibling of a man with severe cerebral palsy, as a teacher of children with disabilities / special needs, and as a keyworker in the 1990s with families of neurologically-impaired babies and young children.

C is for Change

Change affects all of us. As practitioners we are affected by changes in our workplace and, if we are in a caring profession, by changes that happen to the people we care for. As parents we are affected by changes in our employment, in our family circumstances and by the changes that happen to our loved ones. Some changes are celebrated. Some are anticipated with dread and when they actually happen might make us want to dash for the exit, reach for the bottle (or our version of it), find a therapist, take anti-depressants or appeal to a higher being. We might go through grief, anger, depression and

thoughts of suicide. We all seem to be vulnerable to change.

We tend to think of change as something that comes along occasionally. But are we not surrounded by change all of the time? Where can we go to escape change? In a place without change babies will not grow, children will not learn, no one will ever fall in love, the hand that holds the pen will never write, streams will not flow and the universe will not carry on expanding. Everything is change and change is everything.

If this is true, then perhaps some part of our upset or anger at change lies in our attitude to it and not in change itself. And if that is true, then we can make ourselves a little stronger and a little less vulnerable. When something feels good; a relationship, our home, our job, or whatever, logic should be warning us that it, or our feeling about it, is probably not going to stay the same forever. We can fall out of love, we might have to move house, we can be made redundant. In the face of an ever-changing world we can gain some strength by listening to a small voice in our head which reminds us that this pleasure, this joy, this satisfaction is almost certainly of limited duration.

The challenge is to remember change at the same time as enjoying the moment. Or perhaps it is by remembering that things do not last that we become free to taste any pleasure to the full. And this coin has another side: Those miserable things that we are struggling to endure; the awful job, the impossible manager, the awkward teenager, the seemingly endless dirty nappies, are almost certainly not going to stay that way very long. They will change too and that thought can be a life-saver.

But we are all human and, unless we have very exceptional awareness and self-knowledge, we are going to be overtaken by change, pleasant or unpleasant, from time to time. Can we do anything to try to protect ourselves from those unwelcome changes that are hidden around the corner and that might make us suffer?

The oriental Daruma doll might show a way forward. Because it has a rounded base and a low centre of gravity it is self-righting when pushed. It cannot topple over even though it can rock in all directions. Is this a survival mechanism for us – to give ourselves a solid foundation so that when knocked we will right ourselves sooner or later? If we can do this, we will have a second advantage of knowing that we will come back up again and then perhaps not falling so far.

Where do we find such a firm foundation? We each have to answer this question ourselves. For some people it comes from faith, for others from healthy living, fresh air and exercise, for others from yoga, meditation, sport, poetry, music, etc. My foundation, in as far as I have one, comes partly from being inspired by other people who have survived, or are surviving, very unpleasant changes in their lives. As a keyworker I took great strength from parents who were adjusting to the death or severe disablement of their infants. I am still inspired by them almost two decades later. Where does your firm foundation come from?

Those of us who are joined to others, in families or in teams, will sometimes share an upsetting change or will have to watch someone close suffer the arrival of something they do not like or do not want. Those with a self-righting mechanism will be able to support those who take longer to recover or are in danger of staying down. And this is another coin with two sides: A person who is still rocking back and to from

something in their own life, no matter how well meaning, is not in a position to help anyone else cope with change – and might even make matters worse.

For many readers of IQJ, a change that is encountered quite often is the great change imposed on a family when a child is born with disabilities. You might have heard a story about Greece and Holland: Parents whose baby is not perfect are invited to think of this as a forced landing in Holland when they were looking forward to a holiday in Greece. All they have to do is sample the delights of Holland and gradually let thoughts of Greece fade away.

I see this story pop up from time to time in newsletters and magazines and I know it is offered in a sincere attempt to lessen parents' pain. I might have re-told the story too simply here, but I see some dangers in this advice.

In my view, any practitioner who offers a bereft family this way of looking at change must be speaking from strength, must have experienced more than one forced landing in Holland herself – and survived them and learned from them. The story can then be part of a process of a one person who has a strong foundation helping another who is reeling and unsteady. Otherwise the advice can appear superficial and unhelpful. Imagine how you would feel next time you are struggling to cope with some very unwelcome change, such as redundancy or abandonment for example, if you are told by all and sundry to think of it as Holland.

On another level, the advice to make a Greece-to-Holland mental adjustment can be misguided. This imagined 'Holland' in which your plane has suddenly come down is not going to be a very nice place for disabled children and families if there is a shortage of necessary resources in preschool and school, if disabled teenagers are bullied, if families with disabled members are impoverished and unsupported, if disabled men and women suffer discrimination in the workplace. Disabled people and families in 'Holland' have every right to hanker after an imagined 'Greece' if in that country society is enlightened in its attitude to disability.

We have discussed two graded approaches to change here: the first is the awareness that everything changes and then a decision to

become strong and less vulnerable to change. The second, in the Holland story, is the ability to transform an unwanted situation into a satisfying situation by a conscious change in attitude. Many readers will have experienced both of these at some level, but the latter 'transformation' approach requires truly exceptional ability when something has happened to cause extreme upset and unhappiness.



A Daruma doll

Discussion welcome. Contact

p.limbrick@virgin.net

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