

**THE HASSLES OF LIVING WITH POST-POLIO:
SOME SURVIVAL STRATEGIES**

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Paper presented at the Polio Consumers Forum, 12th World Congress of the International Federation of Physical Medicine and Rehabilitation, Sydney, March 1995.

I don't need to elaborate on the hassles of living with post-polio syndrome to most of this audience. As Lorenzo Milam (15) a polio survivor wrote:

When (polio) first picks us up and throws us down, we think that we can beat it. Learn to walk; do it gracefully, so no one will know what little we have. Become independent: how do they say it? 'I'll be my own man'. They never tell us about Phase Two: when the ageing nerves begin to weaken. What we learned to do so smartly after the fire had passed over us, we watch disappear again. Our victories last for ... thirty years - and then the referee comes up to us, blows the whistle, and tells us that we're out, after all. What we gained, we lose (p. 59).

As for coping with the problems of post-polio, while the experts such as doctors and therapists can give valuable advice, the true experts are polio survivors themselves. They have tried a wide range of strategies in their own lives and know from experience how helpful these are (or are not) in reducing the physical symptoms and emotional upsets of having post-polio syndrome.

COPING STRATEGIES OF SURVIVORS

In 1988 I surveyed over 300 polio survivors (24) I asked them to describe the treatments that had helped or not helped, reduce their symptoms, changes they had made in their lifestyles in their attempts to cope with post-polio, and the advice they would give to someone who developed post-polio symptoms. Those answers yielded a wide range of coping strategies.

Five years later (25) I followed up those respondents who had post-polio syndrome. (These people were identified using the criteria developed by American researchers (19) which have been shown to be a valid way of detecting people whom physicians diagnose as having the syndrome). Of the 217 people who were mailed a follow-up questionnaire 176 (81%) completed them. The second survey questionnaire systematically listed the numerous coping strategies that respondents had identified previously and asked survivors whether they had used each strategy. If they had adopted it, they were asked to rate it as 'very helpful', 'some help' or 'no help' in relieving physical symptoms or reducing the personal problems of post-polio.

Treatments that Relieve Symptoms

The treatments most frequently tried by survivors are listed in Table 1. (This paper does not consider treatments specifically linked to consulting a member of a health profession eg physiotherapy, chiropractic or a visit to a post polio clinic. These treatments were included in the survey and are discussed elsewhere (25)). In some instances treatments were prescribed by a health practitioner, in other cases they were self prescribed or suggested by a friend. The figures in the brackets beside each treatment listed in the table, indicate how many people in the survey tried each treatment. So while approximately a third or more had taken drugs for pain relief and undertaken swimming or exercise programs, relatively few had tried yoga, counselling or relaxation courses. The treatments are arranged in order from those receiving the most ratings of 'very helpful' in providing symptom relief (massage, hot baths, special shoes, swimming and hydrotherapy), to those receiving the fewest (herbal remedies).

As Table 1 shows, certain forms of treatment provided at least some symptom relief to virtually everyone who adopted them viz massage, hot baths, counselling, drugs for pain relief and special shoes. The figures in the 'No help' column also indicate that some treatments were found by a relatively large number of users to provide no symptom relief.

This was particularly so for exercise programs. Exercise remains a controversial form of treatment for post-polio syndrome (5, 12). Recently Halstead (10) has developed a five level, limb-specific classification system of polio limbs. On the basis of this classification, recommendations are made as to what, if any, type of exercise program should be undertaken.

Life Style Changes that Reduce Symptoms

Table 2 lists the major life style changes survivors have adopted in their attempts to relieve post-polio symptoms. Comparison of the figures in the brackets in Tables 1 and 2 (which show the percentage of respondents using each strategy) indicates that respondents were more likely to have made life style changes than to have tried the treatments listed in Table 1. Every change was adopted by almost a third or more of the group. Almost two thirds or more reported that they now rested more (78%), had reduced their physical activity (69%) and paced themselves (64%). The results show that life style changes tended to be found more helpful in reducing symptoms than most of the treatments listed in Table 1. For example, employing household help, buying special furniture and equipment and making home modifications were found to be very helpful by 70% or more of those who used these strategies. The results also show that all life style changes that were made provided some symptom relief to virtually everyone who adopted them. As the 'no help' column shows, only between 0-2% of survivors reported that they received no benefits from these changes.

Personal and Social Strategies that Help

Beatrice Wright (26) in her classic book on the psychosocial aspects of living with disability identified a shift in values as a helpful strategy for coping. She found that as well as mourning what they have lost, people who cope more effectively with disability begin to shift their interests and involvement to those aspects of life not closed to them. The survey findings listed in Table 3 show this is what many polio survivors have done and the great majority of those who used such strategies reported that they helped. For example, 75% increased their involvement in interests they can still pursue (and only 4% said this was of no help), 72% developed new interests and leisure pursuits, and 65% found more creative ways to use the time they spent alone or resting. Many found that acquiring information about post-polio helped them to cope; 90% read more about post-polio and 89% subscribed to a post-polio newsletter. Only 2% reported they received no help from this reading. Others found that strategies of personal development such as developing their philosophy of life, or becoming a more spiritual person, were effective coping strategies.

It is interesting that while most of the personal strategies adopted were relatively effective (over half the people that used any of them rated them as 'very helpful' and very few users rated them as being of 'no help') the social or interpersonal strategies that were adopted proved more problematic. The social strategies described as most helpful were: asking friends or family members for help (55% and 52% respectively found these to be 'very helpful' but only 39% of respondents had ever asked a family member to help and 19% had asked a friend to do so). People were much more likely to say they had talked with their family (75%) or friends (74%) about post-polio problems but these activities received the lowest helpfulness ratings of any strategies (apart from some treatments). Forty percent of respondents found it very helpful to talk to family members and 23% said friends were very helpful. For 17-18% of respondents these communications were of no help.

Implications of Findings on Coping

The findings of the survey show that polio survivors are using a wide range of strategies to cope with post-polio symptoms and problems. Many of the strategies that they rated as 'most helpful' involved making changes in their lives both at a practical and personal level. These were effective in helping people cope as was demonstrated by other findings from the research. In the five years between the two surveys, although the physical symptoms of most survivors in the group worsened, people became significantly less anxious and depressed about their health (25).

One of the messages that the findings have for polio survivors is that we need to realise our own abilities to cope, and to live creatively with our disability despite the fact that its causes and cure are yet unclear (12). Kat Duff (17) who had chronic fatigue syndrome wrote:

When pain and disability prove intractable... we feel betrayed by the promises of cures that can be found in almost every magazine, and forsaken by doctors, family and friends who cannot really help but keep suggesting another treatment. A man with debilitating diabetes finally told his doctor, 'In the long run, I'll go down this road myself. Neither you nor anyone else can prevent it or control it or understand it for me'(p. 38).

Similarly there is no complete cure for post-polio syndrome although health practitioners can provide treatments that reduce symptoms and prevent, or at least slow down, further decline. The experiences reported by the survivors in the survey reveal that they have broadened their perspective to include other strategies besides medical treatments as ways of coping with their increasing disability. What they found was that there was much they themselves could do at a life style and personal level that reduced symptoms and feelings of unhappiness.

THE NEED FOR SOCIAL SUPPORT

The responses of survivors to the survey questions concerning social support are of concern. The results show that many respondents are reluctant to ask for practical support from others. When they tried to talk with their families or friends the results were less than optimal. Even among those who talked about post polio with another polio survivor only 43% said it was very helpful. Thus quite a number of survivors lack helpful social support of either a practical or emotional nature.

This is of concern as much research has shown that the support of family and friends can significantly reduce the stress people experience in difficult life situations such as illness (9). Campbell (4) found that family support had a very significant buffering effect for women with more severe post-polio syndrome. They were much less depressed and were more accepting of their disability than their counterparts who had little social support.

Interference from the Past

Answers that respondents gave to other questions in the survey suggest some of the reasons why many polio survivors find it particularly difficult to obtain support from others. The survey asked survivors to write an account of their early memories of when they contracted polio. For most, the initial experience with polio involved separation from their families for extremely long periods with very limited visiting. They suffered from paralysis, pain and frightening procedures and equipment, while being cared for by distant and sometimes

abusive staff. Respondents often described experiences similar to those of Deborah McKeen (14).

When I was five, I got polio. Numerous experiences with doctors, nurses and therapists gnaw at me... Because I had wet my bed I was paraded through a boys' ward wearing a diaper with a bow attached... A nurse made me stay in a particularly painful position because I talked back to her. I can't begin to count the number of times I was left naked, unable to cover myself, on view to anyone walking by. In an iron lung, I remember crying for my mother. The nurse punished my tears by turning the mirror so that I could see nothing but the holes in the ceiling and told me not to be a baby. I *was* a baby; I was five years old. I didn't talk about these experiences to anyone. When I let myself think about them, I felt humiliated, embarrassed, frightened and dirty. It wasn't until I was an adult and in therapy that I came to understand that what I had gone through was not medical care but medical abuse. Silence was the way I avoided confronting my pain. I had done nothing that warranted that sort of treatment; by holding it inside I was not allowing myself to feel the anger I had for being treated so abominably (p. 43).

Such 'care' of sick and disabled children was common until well past the mid-century (11) when the work of John Bowlby (2) alerted people to the long term harmful effects of separating children from their families.

Survivors' written memories indicated that difficulties often continued after their return home from hospital. Negative attitudes toward people with disabilities were more prevalent than today. They were experienced primarily as exclusions that echoed earlier abandonment e.g. parties people weren't asked to, friends who dropped away, venues that excluded or exhausted them, devaluing assumptions people made about them. Some people experienced overt rejection eg teasing and aggression from other children and occasionally even from their own families. Phillips (18) claims that modern western societies regard people with disabilities as damaged goods. As members of society, survivors tended to adopt its standards and to agree that they did indeed fall short. Of course these painful and uncomfortable feelings were rarely acknowledged but they spurred survivors on to become super-achievers. Our mental equation seemed to be that if we were better than average in everything we could do this would cancel out the deficiency of our disability.

Leaving rehabilitation also meant that most survivors lost contact with each other so there was no one in their social group who had had experiences similar to their own and with whom they could talk. Also as Duff (7) pointed out there is a strong social taboo about talking about your disability. People may become uncomfortable because it makes them aware of their own vulnerability or presents them with a problem that is difficult, or often impossible, to solve.

Wright (26) has compared being disabled with membership of other minority groups. However, unlike members of most minority groups a person with a disability is usually the only member of his or her social circle who has a disability. Not only does no one fully appreciate your experiences but they cannot give you useful advice on how to cope. Furthermore, for most minority groups although members' characteristics may not be valued by the wider society they are valued within the person's immediate circle. Thus a Black person in a racist community typically has a family who share his/her experiences, can give him/her tips on how to cope and will instil pride in racial identity. No one ever told us that disabled was beautiful.

Asper (1) has described how such emotional abandonment in youth shapes the adult personality. She has found that as adults such people typically:

- Fail to acknowledge the degree of their early abandonment and suffering
- Fear later abandonment
- Are out of touch with their feelings
- Display false self sufficiency
- Demand impossible standards from themselves
- Feel excessive shame
- Respond to others' needs but have little idea of what is good for themselves
- Are unable to ask for, or accept, help as they fear repetition of their early experiences
- Lack compassion for themselves

Bruno and Frick (3) have found that many of these characteristics typify polio survivors. Such feelings of shame and fears of abandonment and negative responses from others seem to be important contributory causes of the fact that many survivors are not utilising their social networks to obtain support, particularly to obtain practical help. Those that do seek social support usually achieve less than optimal outcomes. It seems that survivors need to develop skills to increase the social support in their lives and enhance outcomes when they do seek support.

There are no simple answers as to how we can achieve this. Asper (1) argued that survivors of youthful abandonment need to face the pain of their earlier experiences. Although this can be very upsetting initially, she has found that it leads people to develop empathy with themselves, it increases their confidence in themselves and their joy in living. Some people have found counselling a helpful support in facing their past. Talking with an empathic and non-judgemental friend may be helpful although many people find it difficult to listen to and support a person who is very distressed.

Small support groups of polio survivors could provide opportunities to discuss the past. One of the most positively received sessions at the Sixth International Conference on Post-Polio and Independent Living that I attended in St. Louis last year was a workshop entitled, 'Polio history: Our stories must be told'. People recounted both negative and positive experiences. Empathising with others' experiences made many acknowledge, for the first time, that their own experiences, which were similar to those of the speakers, were also worthy of empathy. Observing others' courage led them to acknowledge their own.

If you lack a suitable confidant, then writing down your experiences (but not just thinking them over) has been shown to be a helpful way of reducing the distress associated with the past and providing insight into ways in which the past is interfering with finding solutions to present problems (17). Self help books such as those by Wheeler and Dace-Lombard (23) and Dowrick (6) may also be useful support tools.

Any revival of past memories is initially likely to arouse feelings such as distress and anger. Gradually however the past is placed in perspective. We understand that the ways we coped when we first got polio are not the best ways to cope with post-polio. We are now adults, with knowledge, power and resources that we lacked as children or young adults and the world has also changed since then. Attitudes toward people with disabilities are less negative and the majority of health practitioners have been educated to be at least somewhat more understanding of patients' psychological and social needs than were many of the staff recalled in survivors' accounts.

Developing Practical Skills

At a practical level we need to explore strategies for telling others about our needs and feelings in ways that lead to positive outcomes and do not diminish our feelings of self-worth. There is a dearth of 'How-to-be disabled' books. Fullwood and Cronin (8) have written an excellent book called 'Facing the Crowd' which provides parents of children with disabilities with numerous practical strategies for coping with the ignorance, insensitivities and anxieties of the able-bodied. Many of their ideas are applicable to adults with disabilities and could be a useful basis for discussion in the context of support groups. One strategy that they discuss is ways of taking the initiative to shape other people's responses. For example, friends may feel uncomfortable or uncertain when encountering your increasing disability. Often briefly mentioning what is happening, or asking for help, (eg 'I find it difficult doing this now. I wonder if you'll mind giving me a hand?') will put the other person at ease and prevent the situation developing in ways that may upset you (eg feeling your friend wasn't interested enough to ask about your health or didn't care enough to bother helping you).

Other strategies that Fulwood and Cronin discuss include:

- *Managing cliches* (how to react to irritating statements and generalisations people make such as 'God has chosen you for this special burden', 'I think you're marvellous, I don't know how you manage', 'Just look at Roosevelt and Marjorie Lawrence. People with polio have all had wonderful lives and have given the world so much'). Some of the strategies suggested for coping with cliches include: a) Developing short 'pat' answers that can be delivered in a light humorous fashion (eg 'Yes I am pretty wonderful. I don't know how I do it either', 'God has chosen me? I wish he'd asked me first'); b) Non-aggressively repeating the statement back in question form so that the speaker can reflect on its appropriateness (eg 'Do you really think I'm marvellous? What would you have done?') c) Make a statement of feeling or fact (eg In response to 'I think you're marvellous. I don't know how you do it' say 'I don't know either. I do know the going is very tough sometimes') d) Decide to ignore what was said after evaluating the situation.
- *Being assertive* (eg Outlining the dilemma so people have a complete understanding of your problem; providing the ground rules eg family members will need to take turns in taking over a task you can no longer manage).
- *Knowing your own thresholds* (eg when you're fatigued it may be sensible not to visit a critical relative).
- *Developing strategies* for coping with difficult people (eg self talk, mental rehearsal, tension release).

Overall the aim of the book is to help people respond in social situations in ways that increase their own and other people's satisfaction with the interaction. A support group of polio survivors could 'brainstorm' and list social situations members find difficult or upsetting. Then strategies such as those that Fulwood and Cronin suggest could be considered and applied to the problems. Discussion in support groups could also examine the values that underlie much self-defeating behaviour particularly the over-valuation of independence and control which seem to be legacies of polio rehabilitation (3). Trieschmann (22) has identified these values as a major hindrance to ageing with dignity and self-esteem in western societies.

Developing Pride

Finally, learning about the Disability Rights movement (16,21) can help us to understand the meaning of our past and begin to take pride in what people with disabilities have achieved. Polio survivors were the first major group of people with disabilities to be integrated in western society and many have been active participants in the Independent Living and Disabled Rights Movements. Jenny Morris's book (16) has been described as 'a celebration of our strength and a part of our taking pride in ourselves, a pride which incorporates our disability and values it' (p. 14). That is why I prefer the term polio survivor to terms such as polio victim or sufferer or disabled by polio. As Rosen (20) wrote in Disability Rag, 'disabled' is a negative term:

You cannot get away from the fact that 'disabled' means 'not able'. There is no other meaning. 'Survivor' is a real word. It is not negative; it always conveys a sense of wholeness, of skill in just those ways we have had to be skilful. And it defines us both socially and politically within the framework we have had to live all these years. We have survived medically, morally, politically and economically. Those of us who are involved in the struggle to end our oppression are, simply, survivors (p. 8).

And as we continue to survive we are discovering new and different strengths which are celebrated in this poem by Lois Keith (13) who became a wheelchair rider (not wheelchair bound or confined to a wheelchair) as many polio survivors have become.

Tomorrow I am going to rewrite the English Language.
I will discard all those striving ambulist metaphors
of power and success
And construct new ways to describe my strength.
My new, different strength.

Then I won't have to feel dependent
Because I can't stand on my own two feet.
And I'll refuse to feel a failure
When I don't stay one step ahead.
I won't feel inadequate if I can't
Stand up for myself
Or illogical when I don't
Take it one step at a time.

I will make them understand that it is a very male way
To describe the world.
All this walking tall
And making great strides.

Yes, tomorrow I am going to rewrite the English Language
Creating the world in my own image.
Mine will be a gentler, more womanly way
To describe my progress.
I will wheel, cover and encircle.
Somehow I will learn to say it all.

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Table 1 SURVIVORS' RATINGS OF HELPFULNESS OF TREATMENTS IN RELIEVING POST-POLIO SYMPTOMS

| <u>TREATMENT</u> ¹ | <u>RATINGS OF TREATMENT</u> ² | |
|--------------------------------|--|----------------|
| | <u>Very Helpful</u> | <u>No Help</u> |
| Massage (29%) | 67% | 0% |
| Hot baths (28%) | 59% | 2% |
| Special shoes (25%) | 55% | 5% |
| Swimming (31%) | 47% | 18% |
| Hydrotherapy (26%) | 43% | 22% |
| Counselling (8%) | 36% | 1% |
| Yoga (5%) | 33% | 11% |
| Drugs for pain relief (45%) | 33% | 4% |
| Dietary changes (26%) | 30% | 7% |
| Water aerobics (12%) | 29% | 14% |
| Stress management course (10%) | 28% | 17% |
| Exercise program (31%) | 25% | 31% |
| Vitamins (29%) | 25% | 10% |
| Relaxation course (9%) | 23% | 12% |
| Herbal remedies (12%) | 19% | 14% |

1. Percentages of the 176 survivors who had adopted each treatment are shown in brackets.
2. Survivors who had used each treatment rated whether they found it 'very helpful', 'some help' or 'no help' in relieving symptoms. Percentages rating a treatment 'some help' can be calculated by subtracting 'very helpful' and 'no help' percentages from 100 eg 33% found massage was 'some help'.

**Table 2 SURVIVORS' RATINGS OF HELPFULNESS OF LIFE STYLE CHANGES
IN RELIEVING POST-POLIO SYMPTOMS**

| <u>CHANGE MADE</u> ¹ | <u>RATINGS OF EFFICACY</u> ² | |
|---|---|----------------|
| | <u>Very Helpful</u> | <u>No Help</u> |
| Employ household help (31%) | 78% | 0% |
| Bought special furniture/equipment (31%) | 71% | 2% |
| Modify home (31%) | 70% | 0% |
| Pace self (64%) | 62% | 2% |
| Planned life more efficiently (53%) | 60% | 0% |
| Rest more (78%) | 54% | 1% |
| Reduce physical activity (69%) | 52% | 1% |

1. Percentages of the 176 survivors who had adopted each change are shown in brackets.
2. Survivors who adopted each change rated whether they found it 'very helpful', 'some help' or 'no help' in relieving symptoms.

Table 3 SURVIVORS' RATINGS OF THE HELPFULNESS OF PERSONAL AND SOCIAL STRATEGIES IN COPING WITH POST-POLIO PROBLEMS

| <u>STRATEGY USED¹</u> | <u>RATINGS OF HELPFULNESS²</u> | |
|--|---|----------------|
| | <u>Very Helpful</u> | <u>No Help</u> |
| Become more involved in interests I can still pursue (75%) | 65% | 4% |
| Developed my philosophy of life (65%) | 63% | 4% |
| Read more about post-polio (90%) | 60% | 2% |
| Become a more spiritual person (developed my inner life) (62%) | 58% | 12% |
| Subscribed to a post-polio newsletter (89%) | 56% | 2% |
| Asked friends to help (19%) | 55% | 3% |
| Asked family to help (39%) | 52% | 4% |
| Used times I'm resting or alone more creatively (65%) | 51% | 9% |
| Developed new interests and leisure pursuits (72%) | 50% | 7% |
| Joined a post-polio support group (65%) | 44% | 11% |
| Talked about post-polio with other people who have had polio (68%) | 43% | 7% |
| Talked with my family about post-polio (75%) | 40% | 17% |
| Talked with my friends about post-polio (74%) | 23% | 18% |

1. Percentages of 176 survivors who had used each strategy shown in brackets.
2. Survivors who had used each strategy rated whether they found it 'very helpful', 'some help' or 'no help' in coping with post-polio problems.