

CHAPTER 5: ATTITUDES, STIGMA AND HANDICAP

I can't stand people around me [during an attack] or anything like that. I've just got to be left alone, really. I think you just feel, you know, if you could be shut up in a little room on your own you would be all right.

This statement vividly conveys the conviction, shared by the vast majority of sufferers, that vertigo is fundamentally incompatible with any kind of social relations, and is therefore best endured alone. Some people make an exception for family members, who can provide much-needed reassurance and support:

I don't want to see anybody, just want to be quiet -- you just feel that you want somebody in your family to be with you.

I mean, as long as my husband was there it would never worry me, as long as he was here ... the first few months when I was feeling so badly he used to pop home during the afternoons, he used to ring several times when I was home to make sure I was all right.

Nevertheless, one individual actually commented that she was relieved that she lived alone, as it gave her an opportunity to be ill in private:

I just would go and sort of creep indoors and I would be fine in the morning. Sometimes it can be quite nice to think I feel really awful, but I can go home, crash out -- go to sleep or lie down or whatever -- and nobody's particularly bothered.

Of course, to some extent this almost instinctive desire for solitude stems directly from the disorientation and malaise itself; social withdrawal is thus partly an inevitable response to the physical discomfort and incapacity that vertigo entails, just as apathy, fatigue and depression are also recognised elements of the disorientation syndrome. However, from the accounts of those with recurrent vertigo it appears that apprehension about the effect vertigo may have on relationships is the principal motivation for social withdrawal. Similarly, in the previous chapter it was noted that, in a sample of hospital outpatients with vestibular disorders, handicap was more closely associated with fear of embarrassment or social inadequacy than with any anxiety about physical illness or disability (Yardley, 1993a).

The concerns of people with vertigo regarding its potential social impact can be best understood by reference to the concept of "stigma", as defined by Goffman (1963). According to Goffman, an individual carries a stigma if s/he is unable for any reason to fulfil society's stereotypic criteria for normality; stigma may consequently arise from any deviation from expectations concerning the appearance, capabilities or behaviour considered normal for a particular social identity. If this deviation is immediately obvious (e.g. physical deformity) the person is at once "discredited". Failings that are less obvious or may be concealed (e.g. incontinence) render the individual "discreditable", in the sense that his or her apparently normal social identity is vulnerable. The

accommodations to their status open to discreditable people differ considerably from those available to the discredited; a discredited person must adopt a stigmatised identity, while a discreditable individual may prefer the effort and risks attached to trying to "pass" as normal to the frank stigma of admitting the discreditable attribute.

It seems intuitively plausible that people with chronic vertigo may feel themselves to be discreditable; their dizziness may at one time or another prevent them from performing various normal social functions, yet they may be able to conceal this by attempting to overcome the dizziness. However, if the vertigo and ensuing disabilities become obvious, or indeed are freely disclosed, there is the risk of true stigmatisation and possible discrimination or humiliation. It is interesting, in this context, that Nobbs (1988) specifically mentions "anxiety that one's credibility may be questioned" as a fear commonly expressed by people with Ménière's disease. Moreover, the terms in which sufferers express their desire to avoid public knowledge of their dizziness, repeatedly contrasting "normal" and "natural" conduct with the "foolish" or "stupid" behaviour caused by vertigo, strongly suggest that they do perceive it to be a potentially stigmatising condition:

As long as my tablets are up to date then I know that I shan't make a fool of myself, and I haven't yet, apart from one really bad attack when I was really ill, and I was really glad that it was just dark.

My main worry about it [vertigo] is other people seeing me, because of what they might think -- it does look awful.

You don't sort of phone up your friends and say "Oh, I've got an attack of vertigo", you just don't think about it.

It's not really dinner table conversation that you go divulging all over the place.

To be honest with you, there are not a lot of people I have told that I have this problem. I just try and get by without telling them. I do have to tell them sometimes because of certain things I can't do. I can't go up and down a lift maybe, and I will say "I'll take the stairs and I will see you at the bottom" ... perhaps I am embarrassed about it, perhaps deep down I think "What a fool. People think you can't go down an escalator".

As the preceding statement indicates, people with vertigo may feel themselves to be discredited by their inability to carry out normal activities:

When you sort of tell somebody that you can't walk along the road they look at you as though you're stupid, because it's such a natural thing to do.

In addition, most sufferers believe that it is difficult or impossible to explain their unusual and, in a sense, "invisible" condition to others:

I think that unless you can see that there's a broken arm or leg, people can't see that you've got a difficulty. I think that it's very hard for people to realise that you've got a problem, because you can't see anything, I mean to everybody else I looked perfectly fit.

I think people are a bit worried about illness, because, I mean they don't seem to -- if they're not ill themselves -- it's hard I think to visualise someone who's not feeling quite right all the time.

It's not the sort of thing you normally go around saying; "Oh dear, I nearly fell into those bushes" or "I nearly fell back down the steps" or "I've fallen down the stairs" or something. [you feel] a bit strange talking about feeling dizzy and noises in your head, you know, not the normal sort of conversation. It's alright, you see, if you say you've got a terrible pain in your side, or your back aches, those normal sort of things.

These accounts demonstrate intuitive awareness of the parameters which determine how others are likely to react to deviant behaviour; in particular, the disquiet caused by departures from normality which cannot be easily accounted for by visible impairment or common ailments. Many sufferers therefore assume that, in the absence of any obvious explanation for their abnormal behaviour, strangers and acquaintances are unlikely to proffer the sympathy and assistance which people with more common or conspicuous disabilities might reasonably expect to receive:

I don't think the majority of people would rush over and give you a hand, quite honestly. I think that if you were just standing there I think people would be wondering why you were like that.

Indeed, the most commonly reported bystander reactions to a public attack of vertigo are bewilderment and distancing, which provoke a corresponding profound sense of isolation and humiliation on the part of the person with vertigo:

I was tottering, so everybody stopped and watched me tottering, and no one came over just to hold my back and stop me falling. Everybody carried on, and nobody came up and said "Are you all right?".

While the stigma attached to deviations from normal behaviour caused by imbalance are quite sufficient to induce social embarrassment, an added problem faced by people with a little known disability such as vertigo is the risk that people will misattribute the cause of their behaviour:

I think that if you've made arrangements to go out and then you have to put it off because you've got an attack, it's very difficult for anyone to understand unless they've had one. They might

think it's an excuse -- they've never said, but you wonder if that's what they feel, "Oh, they didn't really want to go".

In particular, the intrinsic stigmatising quality of vertigo is greatly augmented by the perceived likelihood of the vertigo being mistaken for the much more stigmatising condition of public drunkenness or alcoholism. The accounts of many sufferers confirm that this is not an unrealistic fear:

There's always the remark when I make a joke about it and say, "Oh, well I can get dizzy on a glass of orange juice". There's the feeling "Is she sort of quietly hitting the bottle?" That does worry me, because as one that hardly drinks at all it's not a very nice handle to have stuck on you at all.

I mean, I know that there are some people that people think they've been in a pub all day long ... I mean, your balance does go just a little bit occasionally, and they, well "You've been ..., had a tippie too many" or something like that. I mean you haven't even been -- it would've been nice to have had a drink, haven't even had a sniff of one ... I mean, I bumped into a woman one day in a shop, and I said "Oh, I am sorry, I lost my balance", and she said "You will be sorry".

Misattribution of the cause of imbalance, as the preceding account illustrates, can transform the reactions of strangers from uncertainty and avoidance to outright condemnation or even antagonism. Sufferers are aware that symptoms of vertigo are likely to be attributed to drink if any aspect of their circumstances make such an attribution plausible; attacks occurring at a party or pub are therefore very likely to be misinterpreted:

When you [lose your balance] other people are going to -- especially if you're at a party -- they're going to think you're drunk ... it's falling over in public at a place where they've got alcohol [that is worrying], and I thought "Well, I don't want to get that sort of reputation".

Factors such as age, appearance, and the time of day also influence strangers' interpretations of an attack on the street. As a result, a teenager who had developed Meniere's disease (highly unusual, but not unknown at his age) found that bystanders' reactions tended to be hostile:

Some people are horrified, they do not know what to do. If they see someone who they think has inflicted this on themselves by drinking, they're going to say "Well, sod you now, get on with it". I think you can get passed on the street -- you'd be desperately ill and people would walk past you because they think that you were drunk. Several people when they saw me thought I'd been on the bottle -- I had comments on the street if I had an attack on the street.

There are several ways in which people can react to the possibility of stigmatisation. Some are determined to overcome the stigma by correcting the ignorance about vertigo that they encounter:

I wore a Medi-aid bracelet for a long, long time with inside literally written "I am not drunk, I'm having a Meniere's attack".

I think sympathy and support is very important [during an attack]. I always say to people who think I'm drunk "Well look, I'm sorry, but I've got a problem". I usually tell people, for instance in an office, "Look, I've come over all queer, there's some pills in my handbag, and just leave me alone".

Having explained their condition, many people found that they then received generous assistance and sympathetic understanding. An additional strategy, which can help to reduce the sense of personal insecurity which potential stigmatisation can induce, is to seek the company of what Goffman has termed the "wise", i.e. fellow sufferers. The support which can be provided by people who have experienced the same problems is especially valuable, not only because no shame or stigma is attached to the shared difficulties, but also because the information they provide is perceived as more accurate than that given by the uninitiated (Cohen, 1992). Several people commented that they felt it was, or would have been, beneficial to discuss their condition with fellow sufferers:

It was nice to actually meet someone else that knew what was going on or knows a similar experience, and to actually get a little bit of understanding of it. It was interesting to meet him and chat to him, it was helpful in a way ... It was just nice to actually chat to somebody who really understood what happens, because it is all very well describing your symptoms to someone, but unless they are actually suffering with it they don't really know what the experience is like.

I could have been helped right from the start if I could have spoken to somebody [who was a sufferer]. If you could talk to each other you could find out from each other what was going wrong and I think you would probably help somebody.

Nevertheless, the general dislike of stigmatisation is such that the majority of people with vertigo choose to attempt to conceal their infirmity from all but a few relatives or close friends:

I'd only tell people that it would affect -- I wouldn't tell people, you know, as a rule of thumb.

I try not to talk about it. I think it's embarrassing when people keep reminding you and they say "Well, how are you?" and "Is it better or worse", and you've sort of got to explain.

This strategy results in the dilemma that an unexpected attack of vertigo might at any time undermine their "normal" identity and necessitate informing and involving people around them. One method of coping with this problem is to present some alternative, more socially acceptable, reason for any temporary lapse in normal behaviour:

I just say I'm not feeling very well, because it's such a long-winded thing to go into, unless it's people I know. I just simply say "I just feel a bit sick, not feeling too well, must be sickening for something".

Another common solution is to involve selectively just one or two relatives or close friends who can be relied upon for discreet assistance:

I don't go away with a friend or anything like that, we always go together -- L [husband] understands and knows.

If I phone a friend and she says, "Oh, so and so is coming as well" I say "Well look, I'll tell you how I feel so I won't have to explain to them what is wrong with me" -- I hate that.

Thing with this is that if you've got a support like a husband or a wife, whichever one of you, then it is not so difficult because you can go out with them and hold on to their arm, and it's not so bad.

Goffman describes this tactic precisely, and notes that these confidants are then expected to fulfil a number of duties, including helping the stigmatised individual to "pass" as normal. Hence, people with vertigo can avoid exposure of their dizziness by leaning on the arm of a relative when they feel unsteady, or may rely on their confidant to make plausible excuses and take them home quickly if a sudden attack occurs in public.

Despite these partial solutions to the problem of stigmatisation, as the correlation between handicap and fear of social inadequacy would suggest, many people are so distressed by the social difficulties attendant on an attack of vertigo that they simply try to avoid situations in which they might be discredited:

I'm not going to put other people in the situation if I can where I would be a liability.

Like, when we go out for a meal, I don't want to accept to go because I never know when I'm going to be bad, and you don't want to upset other people. I've had an attack in a friend's house and they were bewildered, they didn't know what to do. But my husband said "Just let her lie down for a minute, she's not too bad". But of course it puts other people off. It feels as if I'm drunk, and a couple of people have said "She's been drinking again", and I never touch alcohol you know. You can explain it to other people, but I think unless you've got it yourself, other

people don't understand what it's like. Very, very difficult. Like, if you're walking up, you're going like that [gestures a swaying motion] and people sort of look at you, you know ...

Naturally, avoidance of social activities and roles can have serious detrimental consequences for both the individual concerned and for their family. Moreover, when these difficulties interfere with occupational roles and demands, the consequences can be especially far-reaching. The problems associated with work that people with vertigo may encounter are considered in more detail in the following section.

Occupational difficulties

For most people with vertigo, the determination to conceal the vertigo and pass as normal is even stronger in the context of work than among friends or strangers. For example, one man whose general inclination was to be open about the vertigo -- "I think that if you explain to other people the problem then they understand it" -- nevertheless admitted that:

My work -- shall we say that I have to keep it [the vertigo] a secret; if I was with my bosses or the people I work with, I wouldn't say a word.

However, the daily social exposure which employment entails, and the constant necessity for movement, travel, and physical and mental activity, result in a particularly high risk of being discredited. Since few sufferers are entirely successful in disguising their difficulties at work, most are eventually obliged to cope with the consequences of disclosure. Many find that their employers and colleagues are supportive, and may even adopt the role of confidant which family members play at home:

The girls [at work] were very good, that were under me. I'd say "Oh, gosh, I've got a funny attack", and they'd cover, you know, and we'd sort of work it together -- they were very good.

Others are less fortunate, and experience a variety of forms of stigmatisation, which may even culminate in implicit or explicit pressure to leave work:

They [work colleagues] used to fiddle their time, they would say they were sick and have time off, but we knew between ourselves what they were doing, so when I started this [vertigo attacks] they thought I was doing it, but I wasn't doing it at all. The supervisor used to sort of wonder too, because I looked so well before and after. It wasn't pleasant, because I knew I was genuine, I did think once or twice "Oh, blow them, I'll leave" ... [The Welfare department at work] said to me one day -- one of the senior ones -- she said "Have you thought about taking early retirement for this [vertigo's] sake?", so I said "No, I haven't really", so she said "Well ... " and she sort of had a chat to me about it and said "Well, you think about it ..."

There are others [work colleagues] that, um, "You shouldn't be working", "You shouldn't be here", "You shouldn't be in a position of responsibility, right", "You shouldn't be driving" -- well, you name it. They want to get rid of me, they want to get me out of the way because it's worrying them, it's embarrassing them. My job was threatened, they wanted to retire me early against ill health. [I felt] A young man, young family, that's it, all washed up, what am I going to do? "I'll be O.K." [I'd say], "I can carry on work, I can carry on with my shift, there's no problem, I've had my tablets, I'll be all right" -- anything to reassure everybody that I was going to be O.K. and that the job was going to be O.K.

The response of many people, as these accounts illustrate, is to redouble their efforts to demonstrate the ability to fulfil normal roles and duties. Nevertheless, some sufferers ultimately decide that it is fruitless to endure the stress and tension of attempting to live up to the practical and social demands of their occupation. In one survey of a hundred patients seen at a hospital clinic for people with vestibular disorders, half of the respondents reported occupational difficulties, and eleven per cent of the sample had changed their job or left work altogether because of the vertigo (Yardley & Putman, 1992). In a second study of one hundred and twenty-seven hospital outpatients, two-thirds of those who were employed stated that the vertigo caused problems at work and ten had been obliged to change the nature of the work they did, while among the fifty who were unemployed thirteen had given up work because of vertigo (Yardley, Verschuur et al., 1992).

A variety of factors determine whether the vertigo will be compatible with continued employment. Inability to carry out necessary tasks, such as driving or scaling heights, together with repeated unpredictable absence from work, tends to create an uneasy relationship with employers and colleagues. This can itself provide the motivation to leave, as the precariousness of the sufferer's occupational status may be a cause of persistent anxiety:

You feel that, you know, well how long are they going to employ me on the work they give me now? I mean, somebody is going to say "Well, we can do without him because we've got to cut down on staff, and he's the first one to go", so that's the way you feel now.

The decision of some sufferers to leave work is directly due to the stress and fatigue of ill-health, but others are primarily troubled by their inability to fulfil occupational duties:

I was upset that I thought it would be stupid to put other people in my charge, and therefore I wouldn't take the job.

I've stopped teaching, because I think the teacher ought to be able to do what she's telling the class to do, and if I can't lie on the floor it's ridiculous, because a lot of it is done down there.

Interestingly, whereas many people with permanent and substantive disabilities choose to fight occupational stigmatisation by asserting the rights of the handicapped, most people with vertigo are acutely aware of the employer's perspective:

I always feel that if I'm employing somebody you can't afford to employ somebody who's always being ill. How many small firms could afford me now? They couldn't, could they? So I just feel lucky that I work for a large firm.

I was off so long they couldn't -- 'cause they're only a small company and they need as many people as they can get -- and I was off so long they couldn't cope without me, so they had to get somebody else. I understood, because you know they have the right to do it because, you know, they can't really let their business go because I'm feeling ill.

In the case of people with temporary and partial disabilities such as those caused by vertigo, agreement with the logic and attitudes of former colleagues may act as a protection against stigmatisation in a different way, by asserting the identification of the individual with normal society, rather than with any disabled sub-group.

Nevertheless, for those obliged to give up work because of vertigo, the combined impact of the change in social roles and the abrupt drop in income could be far-reaching, as a former van-driver explained:

I am relegated to the role of looking after the house and looking after the kid and so on. Financial problems and everything associated with being out of a job -- it comes quite hard ... I worked long hours, mostly six days a week, so there was not a lot of leisure time as such, but what time there was we did tend to enjoy, but now we are very restricted in what we can do, mainly through finance ... We did have a problem within the marriage, but that was not so much through the lack of being able to get out and socialise but more the stress of me actually being in a position where I was not working, where I could not do an awful lot. The financial worries are big, and it just all sort of built up.

In the following section, the effects of vertigo on the family, and family reactions to the problem of vertigo, are examined further.

Vertigo and the family

The vast majority of people with vertigo report that a few relatives (or occasionally close friends) constitute their principal source of support, and that their help is invaluable. Comments from both married and widowed individuals suggest that the spouse, in particular, plays a central role in enabling them to maintain a fairly normal lifestyle. As noted in the first section of this chapter, such "confidants" may assist the vertigo sufferer to "pass" for normal in public and to cope with routine activities.

Sometimes the assistance required of confidants will consist of actual physical support -- literally, a shoulder to lean on, or help negotiating stairs or getting home. However, the nature of the support which close relatives or friends may contribute is multifarious, as illustrated by the written replies of forty people with Meniere's disease to the question "Is your confidant able to help you feel better when you are upset? If so, how?" (Austin, 1992). Simply knowing that if a sudden attack of vertigo occurs there is someone who understands the problem and who will offer discreet practical aid can be sufficient to give sufferers the confidence to continue with valued pastimes and social roles; several respondents indicated that their confidant helped "just by being there", "just knowing someone is there is enough". Many people also highlighted the way in which their confidant sustained them "by sympathising and helping me not to feel guilty if I can't do things", "by providing support and being totally understanding", "sympathetic and tries to keep me cheerful" (Austin, 1992, Appendix 8). Others noted appreciatively that such emotional support was supplemented by tangible or instrumental support: "practical help with chores"; "patient and understanding and a great help when I am literally on the floor"; "moral support and practical support, e.g. doing the household chores when I have an attack, nursing me".

Research into the mental and physical health benefits of social support indicates that the family may play a particularly important role in protecting individuals against the stress of illness (Argyle, 1992). Jacobs (1992) suggests that open communication and shared problem-solving within the family are important, and many of the responses to Austin's survey confirmed that one of the principal ways in which confidants could help sufferers was "by just listening", "by talking through problems as they arise", "just being able to talk and get my innermost thoughts out", "by being there, sympathetic and bracing", "being realistic about when I need to rest and when I need to be active". As the preceding comment suggests, one of the central functions of such communication is to facilitate the negotiation and planning of changes in roles and patterns of work-sharing which illness may necessitate (Corbin & Strauss, 1985; Jacobs, 1992). In addition, discussions with confidants can provide "appraisal support" (Schwarzer & Leppin, 1992); trusted intimates may thus help the sufferer to evaluate the extent of the threat they face, to identify possibilities for effective coping, or to construct positive meaning in their situation. It is interesting that many confidants use the technique of "downward comparisons" with people perceived as having worse problems in order to encourage the sufferer, according to the descriptions of appraisal support given by Austin's respondents:

[The confidant helps when I am upset ...]

By discussing what I can still do, and how much I have been able to achieve despite the handicap of Meniere's, and how much worse it could be.

Listening to me, particularly tells me there are others with more serious problems, makes me a cup of tea!

By letting me rest is need be and reminding me of other people

(friends/relatives etc) in worse circumstances

In a study of women with cancer, Taylor (1983) has observed that downward comparisons appear to be an important method of bolstering the sense of mastery over the illness and enhancing self-esteem. In addition, some family members use explicit declarations to provide what Schwarzer & Leppin (1992) have termed "esteem support", and to ensure that chronic illness does not undermine the sufferer's sense of identity and worth:

My husband keeps assuring me of my worth within the family as this is my biggest worry that I am becoming a burden. He tells me I still make a valid contribution and this is very important to me.

[My confidants help] By stressing that their love or friendship is not conditional upon my health, i.e. by "allowing" me to be ill.

The task of providing support is not without its costs; indeed, the distress of the spouses of people with chronic illness tends to be correlated with the distress of the sufferers themselves, and is often of the same magnitude (Coyne & Fiske, 1992). Moreover, the burden of stigma and handicap may fall as heavily on the family as on the individual (Anderson & Bury, 1988). Jacobs (1992) notes that chronic illness poses problems of "boundary regulation" within the family; family members may be obliged to sacrifice a significant proportion of their personal time and objectives in order to take on the additional tasks created by the disability of their relative -- whether the chores of daily living (housework, shopping, even paid employment) or the work specifically generated by the illness (assistance with bathing or travel, escorting the relative to medical appointments). Jacobs also remarks that chronic illness which is characterised by unpredictability may be especially disruptive to family activities, as the following account confirms:

Obviously, we could never plan ahead to do something, say going out for an evening, because you would never know what I was going to be like on the day. You could plan three or four days ahead, but no more than that really. You couldn't plan a month or a couple of months in advance because you couldn't -- I could never guarantee that I would be fit to go anywhere.

In addition, family members may be prevented from pursuing rewarding pastimes because of the inability of their afflicted relative to accompany them. The restriction of activity and limitation of social contact caused by the illness can therefore result in a substantial change in the lifestyle of those close to the sufferer, which may affect both their quality of life and the social support available to them:

It tends to upset out plans and things sometimes. We used to be very active doing things, we belonged to a rambling club and we used to go barn-dancing, and we had a good social life -- and we still have, but in a different way -- we had to change our pattern

a bit because of it [vertigo] you see.

It's also altered his [the husband's] life quite a bit -- certain things we used to do together, go for long walks, or car -- I can't go in the car very often, that makes me feel bad, it can start me off. We used to go away for weekends to Manchester, drive up to friends -- all that, I just can't do any more.

To the extent that the spouse shares the handicap, anxiety and sense of helplessness associated with vertigo, he or she is also likely to share the consequent feelings of frustration and discouragement:

Well, he [the husband] feels restricted as well, plus when I get these attacks he's hopeless, he can't do anything for me, and so you can see that he's anxious and he gets a bit uptight.

While most families are able to negotiate a shared solution to these problems, the strain on relationships caused by recurrent vertigo can have serious consequences, as in the case of one young man with Meniere's disease who confessed that:

I would think that she [his wife] found it as stressful as I did at various stages ... I suppose it ended my -- or helped end -- my marriage, because there were times, well, a whole year when I was worse, so I couldn't help.

Awareness of the costs of providing support to a person with chronic illness leads some people with vertigo to conceal their difficulties to some extent even from their closest confidant:

I try not to show too much to him [the husband], I know that it pulls him down.

Often I don't even say to my husband that I feel like it, because I seem to always be feeling like it, you know, and I don't sort of let on, you know -- it's a strain to do that.

Moreover, the spouse is not always entirely supportive. The frequent absence of positive test results or diagnoses, and the vague, unpredictable nature of the symptomatology, can raise doubts concerning the authenticity of the illness even in the minds of close relatives, as two women, who both eventually received a firm diagnosis of balance system dysfunction, discovered:

I think he [the husband] feels with me that it is sometimes self-induced, that I get worked up about things and therefore I get it.

My husband just dismissed it in the end because nobody had come up with an answer. It was obviously me and nothing else. I think he thought I could put it at the back of my mind and it would go away.

It is possible that such reactions constitute another instance of unintentional "victim-blaming" (see Chapter 2) provoked by the persistent and apparently insoluble problems associated with recurrent vertigo. Harris (1992) notes that confidants sometimes withdraw their support if repeated crises result in what appear to them to be excessive demands for succour, and that rejection by the person from whom support was anticipated is the most distressing form of social support failure. She also observes that criticism by the confidant frequently takes the form of accusations of over-reacting to the stressor or failing to cope appropriately. Certainly, the strain of accommodating to the demands created by vertigo occasionally results in accusations either of provoking attacks by overactivity, or conversely, of hypochondria. When these contradictory accusations are levelled at the same individual, the effect is to exacerbate the classic internal conflict experienced by people with vertigo regarding the optimum balance between rest and activity:

You feel guilty about not being able to cook, because, you know, your husband's been out at work all day -- I feel very guilty. My husband will come in and get cross with me because I've tried to do it [cook a meal], which then causes a problem ... He's very good, he looks after me very well, as long as I don't try. He really is very, very good, he gets on with the food and things, asks me if the Hoover's disturbing me. If I had an attack at the weekend when he's home, he would have to do the housework and look after me and get the food. [then] He'd be fed up when he has to go back to work on Monday, and he might mention it in the week, "You always seem to be bad weekends" or something.

The psychological costs of having to rely on family or friends for assistance are not confined to those who provide the help. Dependence upon others restricts the possibilities for activity in numerous small but cumulatively frustrating ways:

You can't have a shower unless somebody's there -- you have to get up very early in the morning to have a shower because the husband goes to work or you have to have it in the evening before you go to bed.

You tend to wait until somebody can go out with you -- I mean that is the main problem.

Many people with vertigo also feel a sense of inadequacy, humiliation, or guilt at being so dependent:

I don't like being taken to the loo by my husband, I think that's -- even with [him] -- it is so degrading, I find it demoralising, I really do -- see that would upset your sort of confidence really

You can't restrict other people all the time, because that's what

you're doing, you're saying "Well, don't leave me on my own", or you're saying "Please come out with me" -- its very, very difficult.

You're relying on other people so much it hurts, because you're losing all your independence. I mean, very often, I get a bit fed up of being indoors and I think to myself "Oh, I'll go up to my mum's" and then I think "Oh, well I've got to ask my husband during the day to come up with me -- not that he minds, he never complains. Or we've got to go to the hospital [for speech therapy], I've been going twice a week, sometimes three times a week, he's got to leave everything and come with me. It's always relying on somebody, and you feel, as good as people are, that you're putting on all the time. I mean, I'd give anything occasionally to go into town, walk around, look at the shops, but you've got to keep on all the time asking people -- then I go, and the bus makes me feel bad, and I regret that I went.

Inability to meet the customary obligations of parents or grandparents because of disability is sometimes described as a cause of guilt or humiliation (the first of the following accounts was given by a woman unable to drive because of vertigo):

My friends drive, and I either have to depend on them or my husband. He is really good, he takes me everywhere, but it means he has to revolve his life around my life, and now I have got children as well it is making life difficult ... until I can drive I feel I am letting my children down in a way, because they are not doing things -- my friend takes her children swimming and she just goes, she doesn't have to rely on her husband to take them there, and I think they are missing out to a certain degree.

It does affect me insofar as I feel that my daughter-in-law has two small children, and I feel that they don't ask me to take the children like they do her mother because they're afraid of my taking them in case I have an attack, and in a way I resent that.

Particular efforts are made to try to fulfil parental roles, not only in the practical sense, but more often by concealing the stigma of vertigo when in the company of the children -- at school events, weddings, or on family outings. Relationships with children seem to fall within an ambiguous category somewhere between confidants, on whom the sufferer can rely for support, and the general public, who are not generally expected to know about the problem or provide help. Goffman (1963) notes that young children are generally considered too unsafe or vulnerable to receive information about a parent's infirmity, and many people with vertigo confirm that they attempt to conceal their stigmatising condition from the children:

We hid it away from the kids for a long time -- Dad was having a stomach upset or had eaten something which hadn't agreed

with him.

With the grandchildren I like to stay as normal as possible, I would try not to let them see, the children. I wouldn't want them to be afraid to come to Grandma as she might fall over.

Indeed, one woman described her perceptions of her growing children's changing attitudes in terms of a sequence of progressively more sophisticated stigmatisation:

At the time I think they were quite worried that Mother kept falling over. If I ever did [have an attack in public] with them around I think they would be mortified with embarrassment, absolutely mortified, and would disown me. I think now that they're that much older they probably think that I was secretly hitting the vodka.

Even when their children reach adulthood, parents are often reluctant to relinquish this protective attitude towards them, and when information about the individual's problems is disclosed to offspring there is sometimes concern that these failings might be perceived as "inconvenient", a "liability", or an unwelcome imposition upon them. Accordingly, accounts of adult children's reactions to vertigo suggest that while they are generally helpful, they may show less sensitivity and comprehension than the spouse. For example, one recently widowed woman described her family as "very supportive", but in comparison with the total support from a very close husband on which she had previously relied, her request for help from her son seemed somewhat reluctant, and his response slightly clumsy:

When I had the Meniere's before [the son] was getting a divorce. I was so upset at his situation that I wouldn't have dreamed of impinging on it again, but I did talk to him about it, and I make light of it really -- I don't want the kids to be worried about me. That sounds very noble, but perhaps it is that I don't want them to think that I can't manage on my own -- perhaps it's selfish really! ... [when she had a severe attack while living alone] I was frightened to go up stairs on my own in case I slipped on the stairs and had to be nursed, and it seemed more sensible to get somebody to take me upstairs than to risk falling. And so I rang [the son], and he came and he let himself in, and he'd come with a friend. [the son] doesn't understand it at all -- how could he? Nobody can if they haven't had experience of it, and because like most kids [laughs] -- at his age! ... he's not a kid at all really, is he? But when he meets something he can't understand he makes a joke of it, it's embarrassment really, so he was saying "You've been at the bottle" -- of course, I don't drink so he knew he wasn't going to upset me ... and I sort of played along with it really and I said to him "Will you take me upstairs".

Another woman described her difficulty in persuading her daughter, firstly, to accept the reality of the disability, and then to countenance measures which

might reveal her mother's stigmatising infirmity:

I'm not tying them to me, we've got to each live our own lives and 'cause I didn't want to be a burden on them ... like my daughter, she didn't have any patience with me at all, but then she realised that -- now she realises as I was there for ten months, how I've had to work hard and struggle, help myself, and she realises that I did have a problem ... She won't let me take my trolley out [for support], but I said, "Well look, I'm going to have to hold on to your arm to cross the road, if I feel a bit wobbly then I'll have to hang on to your arm" ... she sort of agreed to that.

In summary, a very few close relatives or friends typically provide people with recurrent vertigo with a variety of forms of invaluable support. Indeed, given the extent to which sufferers usually depend on close relatives to help them maintain a normal identity and cope with routine activity, it seems likely that the availability of such support will influence the degree of handicap arising from vertigo, although to date there has been no research on this specific topic. Nevertheless, dependence upon others can have significant costs for both confidant and sufferer, and may place some strain upon their relationship. The next section provides an overview of the relationship between attitudes, behaviour and handicap, showing how beliefs about the social and physical consequences of vertigo modify behaviour, and how behavioural responses can in turn influence the physical, social and emotional consequences of vertigo.

Self-generated rules and handicap

The preceding sections of this chapter have illustrated how the belief that vertigo and its consequences are socially unacceptable is widespread; people with vertigo view it as a stigmatising condition, the effects of which are unlikely to be understood by others, and may indeed be misinterpreted as drunkenness or hypochondria. As a result, the preferred way of coping with vertigo is to attempt to "pass" as normal, often with the aid of a spouse or other close confidant. The potential consequences of this strategy are threefold; firstly, increased levels of dependence and therefore tension in family relationships, secondly, a constant fear of public exposure, which can lead, finally, to a voluntary withdrawal from the social situations in which the subject feels vulnerable. In addition to concern about seeming odd, foolish, or even drunk, people prone to vertigo are often apprehensive that they may embarrass or annoy others by proving unable to keep commitments or to perform normal roles (dancing, travelling, walking at a normal pace). Some people are so deeply disturbed at the prospect that at any time they might suddenly be disabled that their social persona is profoundly affected:

You can't ever be confident that something's going to work out right. It alters my personality, because I'm quiet, I don't really sort of talk. [When an attack occurs] you feel about yourself "Oh, what a bore", you know. It changes me, I'm distant, I can't -- normally I sort of join in with everything, you know, with the family and everything, but I would go quiet, definitely quiet.

A fear of being discredited frequently provides the motivation for deliberately restricting social contacts and activities, as in the case of other potentially stigmatising conditions characterised by fluctuating symptoms, such as early multiple sclerosis (Robinson, 1988) and epilepsy (Scambler, 1989). It is interesting, in this respect, that a young man with Meniere's disease specifically mentioned that someone with epilepsy had helped him to learn to cope with his condition:

It was, in fact, a young epileptic that I had in the unit who sort of showed me the way, and said if I was worried about having an attack I'd never get out of bed. I've got to get on with life, I've got to do it, and if it happens, it happens, so tough luck if it happens.

Another motive for retiring from a variety of social and occupational activities originates from the desire to avoid provoking vertigo (see Chapters 3 and 4), whether by exertion, travel, stress, physical or mental activity, or exposure to disorienting environments. The restrictions on lifestyle following from both these coping strategies tend to be formulated as self-generated rules governing behaviour, based on beliefs concerning the available courses of action and their potential consequences (Zettle & Hayes, 1982). Such rules may prove truly adaptive, if they derive from an accurate appraisal of the contingencies present in their environment, and thus serve to help the individual to cope successfully with the dizziness. However, self-generated rules are sometimes based on erroneous beliefs, or are overgeneralised across situations and over time. Where inappropriate rules are based on untested or untestable beliefs they may impose maladaptive limitations and constraints upon an individual's behaviour, and a vicious cycle of self-inflicted distress can aggravate the reaction to the original problem. For example, if vertiginous attacks are correctly judged as causing specific difficulties at work this might either motivate a constructive reorganisation of working practices to cope with these problems, or alternatively might lead to the formulation of a general rule that vertigo rendered the individual unfit for work, with consequential premature and unwanted retirement.

There is ample evidence that in response to vertigo, sufferers often do formulate general rules for behaviour based on their beliefs about the probable consequences of activity (Yardley, Todd et al., 1992), as in the following instance of avoidance of a pleasurable social and physical activity, given by a woman with Meniere's disease:

I used to enjoy perhaps going to a dance, but again, there's no way I can be spun around on a dance floor now. I'm worried that if I am spun round, I'm going to, it's going to happen again, it might just bring it on. So I think "No, I'll do what I know I'm able to, and the rest of it, well ...".

Unfortunately, people who experience unpleasant, and apparently unpredictable, symptoms tend to apply these rules over a wider range of situations and longer time-scale than may be strictly necessary in order to avoid dizziness and social

exposure. Such blanket prohibition of activity is a logical strategy for coping with vertigo which is perceived to be unpredictable, but the avoidance behaviour limits opportunities for testing or extending the boundaries of possible action, and may thus perpetuate a vicious circle of diminished self-confidence. Moreover, these self-generated rules, intended to help the individual manage his or her dizziness, can themselves become a cause of depression insofar as they exert rigid and unwanted constraints upon behaviour, often far more extensive than the direct effects of vertigo itself. The result may be an apparently insoluble dilemma, in which people are torn between the fear of provoking vertigo or being socially discredited and the desire to escape a depressingly constrictive lifestyle.

Powers (1973) suggests that the only escape from the dilemma of conflicting intentions is to reorganise one's value hierarchy and define new goals. Unfortunately, the consequences of such a reorganisation are not always entirely positive. A relatively common response to the psychosocial problems posed by illness is to adopt the role of an invalid. This solution gives the individual a new identity and a less ambitious set of goals, and thereby minimises the risk of failure. Such behaviour may also result in "secondary gains" -- receiving attention and sympathy, or being absolved from unpleasant or stressful duties. However, the costs can include relinquishing the prospect of fulfilling many normal roles, accepting the stigma attached to this departure from normal behaviour, and putting strain on social or family relationships.

Another way in which multiple goals may be pursued is through the hierarchical "nesting" of sub-goals (Scheier & Carver, 1988). For example, the higher-order goal of maintaining an idealised self-image is translated into principles (e.g. "be independent"), which, when confronted with a range of possibilities, motivate the selection of a particular course of action (e.g. concealing an attack of vertigo rather than asking for help). This is, in turn, executed via a variety of subordinate acts (finding something to lean on, making up socially acceptable explanations for unusual behaviour, etc.). Scheier and Carver suggest that while behaviour is directed towards a sub-goal this goal temporarily becomes functionally superordinate. The difficulty is that, in the process of dealing with immediate problems, it is easy to lose sight of higher-order goals. An individual may be concerned on a daily basis with avoiding provoking vertigo, or being exposed in public while dizzy, and may seldom reflect on whether their behaviour is detrimental to the pursuit of higher-order goals and principles, such as maintenance of an independent, fulfilling life-style and a positive self-image. As a result, day-to-day behaviour may not be consistent with the course of action that a rational cost-benefit analysis of the problems caused by vertigo might suggest. Examination of the ways in which people with vertigo attempt to regulate the impact of their condition on others reveals a clear contradiction between sufferers' expressed resolution to carry on as normal and to avoid informing or involving others, and their evident need to confide in and rely on people for practical help. This contradiction does not result from a distinction between self-reliant and dependent individuals; the same people frequently state a desire to cope alone, but also give numerous examples of receiving or soliciting assistance. There is also a clear contradiction between many individuals' expressed determination to carry on as normal and the various restrictions on activity that they are actually forced to adopt.

In some cases, this predicament may result in a condition of "learned helplessness" which is believed by some psychologists to be virtually synonymous with depression; if the individual considers that the vertigo has aversive consequences over which he or she has absolutely no control, and if these consequences appear to be extensive and long-lasting, then depression is likely to ensue (Abramson, Seligman & Teasdale, 1978; Mineka & Kelly, 1989). People with vertigo perceive themselves to be helpless in the sense that they are incapable of competently performing many of the social, occupational and familial roles they have previously occupied. They may be physically incapacitated at times, they are unable to engage in a variety of valued pursuits, and their dependence on others has increased. Feelings of anxiety, failure and helplessness may also result from the apparently insoluble conflict between the wish to remain active and independent and the need to limit activity and seek assistance. Moreover, a sense of isolation may be fostered by the withdrawal from social networks, as well as the belief that others are incapable of understanding their situation.

Although somatopsychic processes have been emphasised above (partly in order to highlight the fact that the association between vertigo and distress can be adequately explained without recourse to hypothetical personality disorders), it is likely that predisposing personality traits will influence the degree of handicap and distress caused by vertigo. Pre-existing levels of anxiety are likely to enhance the development of fear of vertigo and stigma, while feelings of personal incompetence may hasten withdrawal from social activities. Similarly, those with low self-esteem may be prone to underestimate their ability to cope with the vertigo, while pessimists are more likely than optimists to conclude that their problems are intractable and over-whelming. However, while self-imposed limitations on activity may reflect a failure to perceive or generate coping strategies or a pre-existing tendency to adopt a helpless, dependent role, they may equally well represent an active attempt to control the situation which then becomes maladaptively over-generalised. Moreover, the links between personality and handicap may be bi-directional, as many people with vertigo describe personality changes which they directly attribute to the vertigo and its consequences:

I used to be very outgoing, I worked all my life as a computer operator, I used to go out a lot, to pubs, with my husband, theatres, dancing. All that, it's out of the question now.

I was a very outgoing person, and I have become, largely because of this [vertigo], very introverted. When you're afraid there's a risk that you might fall over it's not easy to go into a room of people you don't know. Whereas at one time I'd have breezed in and been the life and soul of the party, I couldn't possibly do that now.

The experience of vertigo can thus be seen as the product of many interacting dimensions, which all too often combine to create a vicious cycle of escalating handicap and distress. In order to reduce the risk of provoking unpleasant and frightening symptoms, and to avoid the social embarrassment and stigma they might cause, many people with balance system disorders deliberately

restrict their physical activity, travel and social commitments. However, the resulting loss of valued roles, supportive social contacts and rewarding pastimes may fuel the feelings of anxiety and helplessness initially caused by physical illness. In addition, avoidance of vigorous movement and demanding perceptual environments may prolong the duration of the vertigo by retarding sensorimotor adaptation. Nevertheless, despite this gloomy depiction of the potential for disability and depression, ultimately most people with vertigo learn to adapt to disorientation and to reverse the cycle of handicap. The final chapter describes how it is possible to adjust to and overcome the problems caused by vertigo, either with or without professional help.