

A friend in need

'Getting by' is easier with a little help from our friends, and when ill, we need their support more than ever. But have your friendships stood the test of M.E.? Patricia de Wolfe finds out.

You are well, and like almost everyone, you have friends. Perhaps you go out together to films, concerts, pubs, the gym... Or, with your partner, you may entertain and visit other couples for evening meals. Then you become ill. The outings or dinners become difficult, then impossible. At first, everybody waits for you to recover. But you don't. What happens to friendships then?

Your stories reveal a range of experiences, some deeply painful, some heartening, many mixed.

Friends are chosen, and may be 'unchosen'. Unlike family and couple relationships, friendships are not necessarily expected to last through thick and thin. Although the reality may fall short of the ideal, there is a general expectation that a partner or close relative should be supported in sickness. But few people look askance at someone who neglects a sick friend.

However, friendships matter greatly. While some may not go very deep, others are based on years of shared experiences and confidences, and their loss can be devastating, especially at a time when much else has been lost too.

Harder to gain sympathy for M.E.?

All incapacitating illness affects and may threaten friendships. But many of you point to the particular difficulties of gaining sympathy for M.E.

Lynne was told her illness was a 'luxury' and a 'holiday'. Carla found it particularly hard to get her working-class friends to accept her illness as genuine – to them, she thinks, the diagnosis smacked of middle-class privilege. Karen, having struggled to a party, tentatively mentioned chronic fatigue when asked if she was better. Her hostess shrieked with laughter. 'That's a good one – must try it sometime,' she shouted across the room to her husband. While 'friends' with these attitudes do not always abandon the sufferer, they do not bring great comfort either.

Lost in adversity

Whether or not because of scepticism about M.E., many of you (although not all) report losing friends. Often, they simply get in touch less and less. Sometimes, there is a confrontation. Either way, your stories show that their defection can cause great distress:

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'People I thought were really good friends just disappeared. They didn't even phone. I could never have behaved like that.' 'We worked together and she was my best mate. After I went off sick, it was months before she offered to visit. By then, I was too angry to see her.' 'She said it was too much for her to handle. I thought I was the one with too much to handle. I was stunned.'

It sometimes happens that friends who were initially loyal vanish after a relapse: the realisation that things may get worse rather than better seems to frighten them away.

Occasionally, barriers to friendship come from sick people themselves. Rita stopped making arrangements out of embarrassment at forever having to cancel. Carla feels her anger when first ill may have alienated friends.

More often, however, busy friends find it hard to alter their schedule – or are not willing to sacrifice precious free time for an encounter that can feel difficult. If the person with M.E. is housebound, and there are no more

joint outings, conversation becomes everything, at a time when lifestyles are totally divergent – and when illness may limit the sufferer's ability to talk. (Some people who have lost many friends say that pen friendships have proved the most enduring.) People have to find new ground on which to be together. If this situation continues for any length of time, it can take great commitment to rebuild a way of relating that overcomes these difficulties.

Faithful friends

While some people report the loss of almost all pre-illness friends, many find that at least a few friends remain loyal. They may not fully understand the illness – but they are, basically, there for the duration, fitting in with sick people's limitations, and perhaps occasionally helping out with transport, shopping or childcare. Some continue, over many years, to make regular long journeys to a sick friend's home; to leave when exhaustion suddenly sets in; to arrange social events so that their pal can join in, if only briefly; to telephone, e-mail, send cards.

What people with M.E. want from their friends, of course, depends on their health and situation. People well enough to manage unaided, and those with a carer, are in an easier position than those needing considerable practical help. People obliged to keep asking for favours may resent both their own dependency and their friends' failure to offer help spontaneously. In fact, while friends may help out in a crisis, regular, long-term practical help – a large weekly shop, say – seems more likely to come from a relative.

People without a loving partner may be more emotionally dependent on their friends. Whether support is practical or social, friendships can be complicated by guilt on both sides ('Am I asking too much?' 'Am I doing enough?'). Rachel, severely affected,



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felt some relief when two good friends moved away and contact continued by phone: no more worry about being well enough to see them, or resentment when they were too busy to visit.

It is not always predictable who will offer support: the closest friends may shy away, while former acquaintances become really good friends. People who have already known someone with M.E. seem much more likely to sympathise. Marie found her older friends far more patient and understanding than those of her own age, while Rachel says friends need to need you – and that people who are single or lonely tend to need you more.

Ella's story is remarkable: she moved from abroad to be with her brother, recently discharged from mental hospital, and befriended his friends, also former psychiatric patients. When she became very ill with M.E., several of them banded together to care for her, and have remained as helpers. Their experience of their own symptoms, she thinks, made it easier for them to empathise with her infirmity and her inability to communicate when she was at her worst.

There are, then, some people who value you for who you are, rather than what you can do; and who draw on their own troubles in order to understand yours.

Advice on keeping friendships alive

Many of you offer advice for retaining friendships. ‘Take an interest in your friends’ lives and be glad for them,’ says Lynne. ‘Try not to show jealousy when they enjoy things you have lost. Sending cards to mark their special events shows that caring goes both ways.’ Carla, who had a long – and eventually successful – struggle to mend her relationship with her best friend, believes it is important to confront the emotions that the collapse of a previously hearty person can evoke: memories and deep-seated fears of abandonment and bereavement.

Rachel thinks it essential to take the initiative in contacting friends who are out of touch, hard though this may be. Some people, she notes, feel awkward if they can't improve your situation, but respond warmly to a specific request for help. Ella, nursed by her brother's

friends, and used to giving rather than receiving aid, found accepting help from people with their own problems humbling – but also recognises that feeling needed was satisfying for her helpers. Everyone likes to be appreciated, and making your friends feel they have made a difference is vital to keeping them.

Don't expect too much from any one person, warns Meera. Some friends are best at empathising, others at giving practical help, yet others at making you laugh. Nobody is good at everything. Few people are there for you all the time: commitments change, and support on offer may vary accordingly. And tolerance is needed of friends' failure to grasp what you can and can't do, sometimes despite repeated explanations.

While many of you advise carefully explaining your symptoms to your friends, most also complain that they don't take in what you say. Some gaffes can be shrugged off with a laugh. ('My dear dozy friend Anne still buys me booze – which I haven't touched in 15 years!') But other failures to grasp your limitations reveal profound incomprehension that can

hurt. Even loyal friends who accept M.E. as a genuine illness may seem clueless about what it really means for your daily life or long-term prospects. But, says Alice, 'I look back to when I was well, and I know I couldn't have begun to understand what it was like to live like this. So I try not to get angry.'

Find new friends who also have M.E.

Whether or not old friends remain, contact with other people with M.E. (via local groups, e-mail, or telephone) is usually highly valued: there is no disbelief, no need to justify yourself... These people understand how frightening a relapse can be, what effort can go into an outing or even a phone call. You can exchange jokes about your experiences of being ill. Many lasting friendships arise, and a few of you report that most of your friends also have M.E.

There are occasional reservations. People are affected differently, and not everyone understands your symptoms. Paul feels out of place in M.E. groups because he has largely recovered – although also out of place in the wider world because of years of illness. Joan finds other sick people too self-absorbed. And several of you, despite appreciating the empathy of fellow-sufferers, say that having the same illness is no substitute for a common interest. Some people who have regained sufficient energy have taken up new activities such as creative writing, and have succeeded in making new friends who are well.

Perhaps surprisingly, even severely affected people occasionally establish a strong new relationship with someone healthy. But others are daunted by the difficulty of explaining their restricted lifestyle, and feel excluded from conversations. ('I've never even heard of the nightclubs and pubs other people my age go to,' complains Don.)

While affection and long knowledge of each other may sustain links with pre-illness friends, the world of other 'normal' people can seem out of reach.

We would be bereft without our friends in health, let alone in sickness. The bitterness with which you speak of friends who abandoned you, sometimes years after the event, is evidence of this. Friends bring you comfort, make you feel valued, and link you to the world. If you have friends after years of illness, congratulate yourself, and treasure them.

Useful contacts

For details of your nearest M.E. support group, call our Wells office or e-mail admin@afme.org.uk. Alternatively, check out our listings of special interest groups on page 46 such as the internet-based 'M.E. Chat', friendship network Aquamarine and our penpals group.

Still Friends

'Everywhere had become
All those places I once visited,
Anywhere I could no longer reach.
I thought that you would miss me,
Would grieve with me for my losses,
Yet help me seek that which remained
And all that might grow...'

These lines, from a poem by Carli Barry, poignantly underline the importance of friendship to people with M.E. 'Still Friends', which appeared in full in *InterAction* 42, has now been put to music by Trevor Williams to raise funds for AfME. The resulting CD, which contains two other 'M.E. friendly' tracks, costs just £5 including P&P. To find out more, visit www.TrevWilliams.co.uk, or send a cheque payable to 'Trev Williams Music' to Trev Williams Music, Technology House, Lissadel St, Salford, Greater Manchester, M6 6AP.

