

Transition in Chronic Illness

# Fatigue



BOOKLET 6

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1. Constant change: the shifting experience of illness
2. Grief, loss and fear
3. Shifts in self and identity
4. Relationships
5. Sexuality
6. Fatigue
7. Pain
8. Interacting with others
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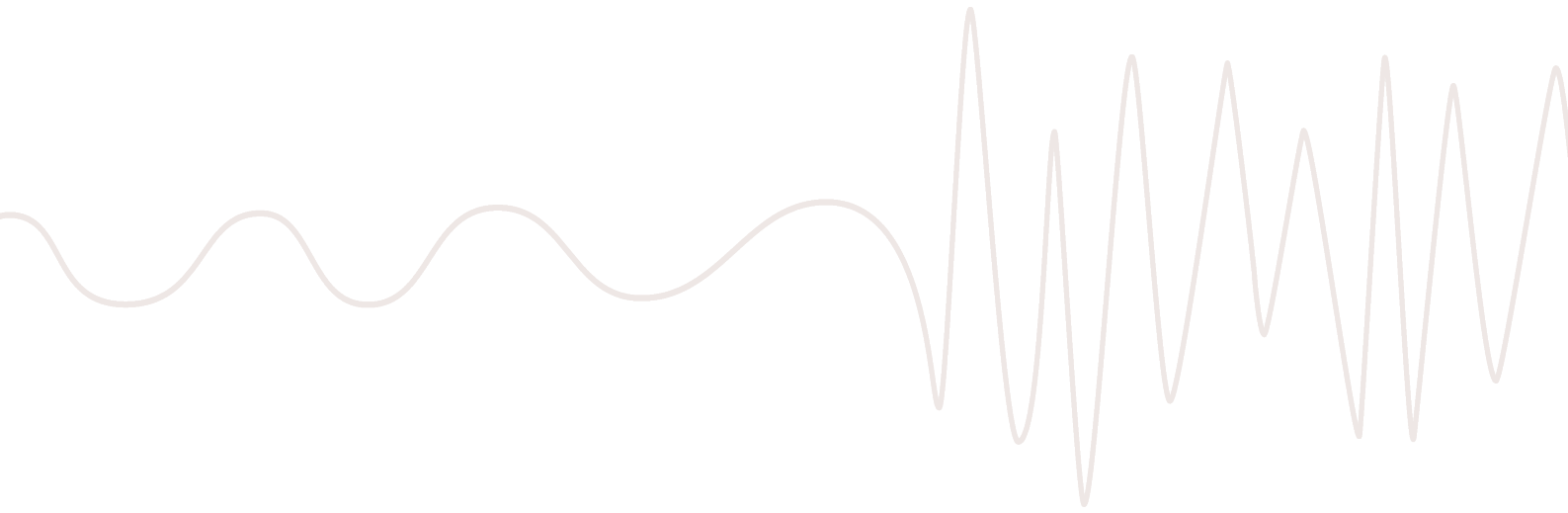
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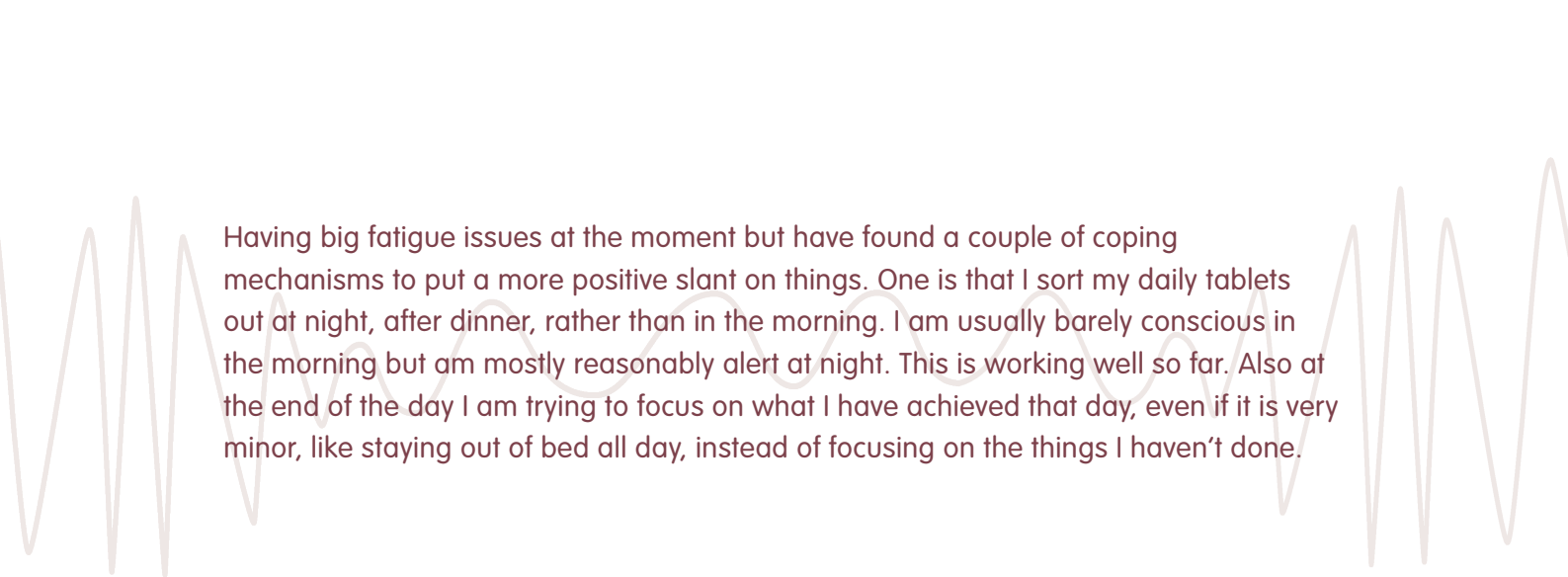
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Having big fatigue issues at the moment but have found a couple of coping mechanisms to put a more positive slant on things. One is that I sort my daily tablets out at night, after dinner, rather than in the morning. I am usually barely conscious in the morning but am mostly reasonably alert at night. This is working well so far. Also at the end of the day I am trying to focus on what I have achieved that day, even if it is very minor, like staying out of bed all day, instead of focusing on the things I haven't done.

## Fatigue and Fog

Fatigue is one of the most common symptoms experienced by people living with chronic illness, yet it is difficult to describe, measure and define. The way fatigue is experienced is unique to each person, but it is very different to tiredness. Since it is usually invisible to others, family, friends and colleagues can sometimes misinterpret fatigue as laziness or lack of motivation; hence there can be little understanding and support for the person experiencing fatigue. Health workers may also dismiss fatigue or fail to acknowledge the seriousness of the effect it has on people's lives. Fatigue may be understood by others to be tiredness that may be resolved by sleep, but this is not usually the case. Fatigue can seriously affect our well-being because it has an impact upon every aspect of our functioning, including physical, emotional, psychological, spiritual and social aspects. Fatigue can alter the way we live our lives.

Some of us experience fatigue continuously and relentlessly. Others find they have episodes that are triggered by events such as stress or exertion. Whether fatigue is continuous or episodic, there is a strong sense that it is better managed by working with, rather than resisting it. While fatigue diminishes a sense of control in one's life, resisting it will surely result in further loss of control.

Fatigue robs us of energy and abilities, and fluctuates widely during a day. It may be experienced as complete lack of energy and exhaustion, inability to concentrate or think clearly, a breakdown of emotional coping skills, inability to participate socially and/or perceived loss of hope, faith and beliefs. The experience could be one, some, or all of these things and this will vary from day to day. Fatigue brings with it a high degree of uncertainty and for some of us, a downward spiral of mood. A lack of understanding and support for people who are fatigued compounds this.

Yet some of us have noted a more positive side to fatigue. It will force us to take the time to be still and restful. This is something that has been hard for some of us to do in the past. Fatigue means different things for each person's life, as you will see in our responses.

## *What is your experience of fatigue?*

I have chronic fatigue as part of my overall illness. This provides me with a lack of energy and continually tired muscles, and a loss of will to be active.

*Graham*

I have Crohn's colitis and when I have a flare up of the disease, which has been quite often over the past two years, I become extremely fatigued. The fatigue is that suddenly an energy seems to have left my body e.g. it is difficult to get out of the car, up off the toilet, chairs and so on. I often ache all over and have a temporary arthritis in the body and legs. I feel that everything I have to do, in particular going out to activities are no longer enjoyable, they are just things to somehow get through. I have the feeling constantly of wanting to lie down on the floor and rest and forget everybody and everything. I just want to be left alone, although at the same time, I don't want to be left alone. When I lie down because I just have to rest, I can lie quietly and enjoy it because I don't have the energy to worry about what I am not doing if I had the energy. I can sit in a chair calmly for quite a long time just thinking and resting.

*Di*

Fatigue is the most constant, yet the most under-rated symptom of my condition. For me fatigue is ever present, varying only in intensity. It is far more than being tired, sleepy or lethargic. The closest comparison I can think of is constant and complete exhaustion. At best my fatigue is ceaselessly having to push myself to get through daily activities, rather than enjoying them. At worst fatigue is overwhelming, mind numbing, all encompassing. It drains the very life out of me, leaving me feeling utterly exhausted and emotionally and physically drained.

*Chrispy*

Fatigue is not being able to do the things you want to do. It's a dragging feeling, like lead, being washed out. Not being tired really in that you need sleep but just the body feeling tired. Drained is another word I'd use for fatigue.

*Julie*

Fatigue can be either mental or physical, but physical fatigue is always accompanied by mental fatigue. I wake up with fatigue and it's a downward spiral throughout the day. Unfortunately my pain worsens with increasing fatigue, so that, for example, both worsen during the course of the day, both worsen when I'm with others, both worsen with exercise, and both worsen when I'm not able to sit with a whole body support (for example in a full-backed recliner).

“Really bad fatigue makes me feel as if someone has stolen my bones.”

My fatigue is alienating (both physically and psychologically) and all encompassing (being both physical and mental). It requires so much effort to make myself do the smallest things, that it really takes the enjoyment away from most things. Notice how I said “make myself” .... that’s basically what it’s boiled down to ..... I have to literally show a lot of determination to do the smallest things. It’s responsible for taking the enjoyment out of everything but the smallest things. Realistically, how much time do I want to I spend sitting and watching a flower bloom, or a spider make a web?

*Iolanda*



One minute you are filled with energy... and the next minute it’s all drained away – Michelle

I have found that I am more tired than I used to be, and don’t have as much energy. This may be due to my condition, changes in my life, middle age or a combination.

*Andrew*

Mind numbing lack of energy. Feeling as if I literally have the weight of the world on me. I feel so heavy. It takes total will power to get out of bed, off the chair, getting in the shower etc. I can feel the energy draining from me. Its like someone left the tap running and it’s MY energy that is running out of it. Its about not being able to think or concentrate and not being able to do anything at all but sit or sleep. It’s more than just tiredness.

*Michelle*

Episodic, draining, frustrating, at times overwhelming. Really bad fatigue makes me feel as if someone has stolen my bones. I think it is an inevitable part of chronic health problems.

*Helen*

For me, fatigue can be physical, psychological/emotional, mental, spiritual. And I guess that when I feel it in one area of my life, it quickly spreads into other areas. Physical fatigue happens to me from fluctuating blood sugars. Both highs and lows are tiring (bring on the headaches, the fluid retention, massive shifts in hunger & appetite, just to list a few). During these times it’s hard to keep up social interests, I drag myself into work, and generally I feel like my life becomes disordered. I feel like I lose control over things that usually matter to me. But then I’m also at that point that I’m too tired to care.

Psychological fatigue happens when I can’t find any more emotional resources to deal with the physical effects. I resent feeling unwell. I resent the fact that looking after myself is a full-time job. This often leads to lapses in positive/beneficial health behaviour. I ‘throw in the towel’ so to speak. Mental fatigue is multi-faceted. Blood sugar swings affect concentration, bring on the brain fog, and

I've described it before like a slow modem connection. You are aware of the process, and it seems to take forever. Sometimes I stop mid-sentence wondering what I even set out to say! Sometimes I become dyslexic, or just one big blubbering mess where I've lost the cognition to say anything coherent. I guess Spiritual fatigue is what I use to describe the feeling of loss of hope/faith or values I believe in. When I get this way, I know I'm close to the bottom and seriously need to make some readjustments in my life.

*Mari*

I often get tired and can work through it to a renewed level of energy. The fatigue I relate to is when I totally close down, need to lay supine, can't bear to be touched spoken to or moved in any way. I don't think or talk straight, I just succumb to being taken away. It comes over me really quickly and I recover sometimes very quickly, can be with in 15 minutes or over days.

*Olympia*

## Adapting Our Lives

Fatigue can change the way we live our life. Like chronic pain, fatigue in chronic illness is not easily treated. We have become aware that we have an amount of energy which, when gone, is not replenished. Therefore, we learn to budget the energy we have. This means that we now make careful decisions about what we do and how we do it, with consideration of the energy budget. For some, the constant lack of energy means that we may not participate in life as fully as we once did. Interacting with others expends valuable energy and so we may become less social. Some of us have found activities that conserve our energy but provide enjoyment, such as using a computer or reading a book. Feeling too fatigued to meet up with friends and participate in events as we once did can result in feelings of loss, sadness and loneliness. We may feel as if there is some diminishing of the joy of life. We may need to have others assist us with some tasks that we are unable to do because of fatigue. Loss of independence to any extent does not come easily but we can learn ways to reduce the impact of fatigue on our lives. We learn to ask for help. For some it may mean changing our living situation, such as living with supportive family members. If we have partners they may take on roles that we once fulfilled. We may find that there is a need to adapt our lives to maximise our rest and to ensure that our energy is conserved. Pacing our activities and planning ahead may help to minimise the impact of fatigue.

### REST

Rest is a large part of my time  
– Graham



### *How does fatigue impact upon your life?*

I lack the drive many times to do anything as my body lacks the energy and my mind loses its drive. Everything appears to require too much effort.

*Graham*

It is more difficult than usual to be good company to others. The lack of energy makes it hard to concentrate on for example, reading, crosswords, playing cards or the like; hard to happily chat; hard to listen to music with a rhythm that I love because somehow I can't respond and the idea of having a rest overwhelms my mind. Irritation grows a little because I know others don't know what I am feeling and I don't expect them to understand.

I find I have to curtail my activities, struggle to get through washing, ironing, washing my hair, bothering to play with the dogs and put off ringing up to make appointments.

*Di*

Fatigue increasingly limits what I am able to do without completely wiping myself out. I struggled to work until the fatigue was so constant and debilitating, I existed rather than lived. I rarely went out, had no time or energy for any personal interests or hobbies and slept half of each weekend away in order to drag myself through another week at work. My husband had to gradually take over more and more of the housework, as I couldn't cope with both that and work.

I'm no longer able to work, but fatigue still impacts heavily on my life. Fatigue doesn't just affect my physical energy, but impedes on my mental ability to concentrate and exacerbates my almost constant state of brain fog and forgetfulness. The worse the fatigue, the less physical and mental energy I have to cope with day to day activities. Some days I can manage some housework, shopping and maybe even some other activity, and on other days can't. Some days I'm able to cope with little more than time on the computer or light reading, but on others I can't even manage these. I may find even following simple conversations impossible. Leisure and social activities are rarely pleasurable but rather something to "get through", therefore severely limiting what activities and social events I am able to cope with.

*Helen*

Fatigue impacts big time. Not being able to go out and if you do, knowing that the next day or few days you will only be able to do a minimal bit of housework if even that. It's struggling through trying to cope but feeling empty. It can be so debilitating that to put one foot in front of the other is almost impossible. Having to go to bed early every night is the only way to possibly even try to cope through the next day. Unable to enjoy just the simple things in life because fatigue takes over and it's just impossible to think about anything extra.

*Julie*

I struggled to work until the fatigue was so constant and debilitating, I existed rather than lived.

My physical fatigue is severe enough for me to have had to move back and live with my parents because quite frankly, I can't do the minimum things for myself. I have trouble holding a phone, let alone muster the energy to cook for myself every night. It severely limits what I can do out of the house too. Getting exhausted after 1/2 hour out of the house really does make it difficult to enjoy anything I do, for example, it's hard to enjoy social activities which are all the more important for me since I don't have much contact with friends anymore.

The frustrating thing with fatigue is that it's impossible to find things to do when you're so tired. I hate television. Reading is impossible too - not only do I have trouble holding both the magazine and my head up without support, the mental fatigue is too bad and I can't sit and read anything anyway. Because of the mental fatigue and my brain injury memory problems, talking books are impossible too. My computer is my companion - almost my best friend - yet as my health is deteriorating with the years I'm finding that I don't have the physical energy to sit at the computer and the mental energy to even read emails. Hence it's taken me 5 days to finish this email. Even enjoying the simplest of things is difficult. I can't even enjoy eating dinner when I can barely lift a fork or spoon to eat with.

*Iolanda*

I don't think that I go out as much as I used to, tending to want to stay at home more but in a way I want to be doing more.

*Andrew*

It's planning everything that I do and everywhere I go and making sure that I can get enough rest time. It means that I have to say no to things that I would really love to do. Fatigue at times has almost total control over your life. You are dictated by it so often.

*Michelle*

My severe bouts of fatigue seem to occur periodically - usually once or twice a week. On these days I usually have to spend the whole day in bed. Other days I can usually struggle thru, although I mostly go to bed about 7.30pm, occasionally even earlier. Sometimes I go back to bed for a while after breakfast.

*Helen*

If I'm feeling a certain type of tiredness I don't venture too far from home, so I'm often last minute cancelling arrangements or avoiding making them if they are too far into my future. My line goes something like this "sounds fantastic I would love to do that, but I'm not sure if I can manage it, can I stay flexible with it". I have to avoid the back to back activities. [MS has] slowed me down, and some good things have come from that. I have become more self directed and self nurturing with my time. As time goes on I'm also better at not letting myself go to that extreme of exhaustion. Sometimes I feel sad about the shared life events that I miss out on. I have mostly overcome my fear of being unseen and forgotten.

*Olympia*

## What Triggers Fatigue?

Over time, we learn that certain activities or events may trigger fatigue. Recognising the triggers assists in avoiding, minimising and managing episodes of fatigue. The two most common triggers we have identified are stress and 'overdoing it', but there may be others to do with the physiology of the illness we have, the medications we take, eating certain foods and poor quality of sleep. Hot weather may increase fatigue for people with certain illnesses, as can other symptoms such as pain, infection and depression. Poor diet and hydration may also trigger fatigue. Fatigue can be caused or worsened by other conditions, so it is important to communicate your fatigue experiences with your health worker.

Sometimes the trigger is not within our control, such as an illness flare up. During these times we manage the fatigue as best we can so that we are comfortable and assured that what we are doing is what we need to do in order to shorten its influence.

Sometimes we might decide to ignore the triggers and to continue doing what is important to us. The consequences may be worth the opportunity to enjoy doing something. At these times, we are comparing the worth of being able to do an activity or enjoy an event with the impact of fatigue. Fatigue is always changing, and we find we want to test the boundaries from time to time. We might find there are less consequences than previously thought, and that can open up the opportunity to do a bit more of what we enjoy.

Triggers may not be as relevant for those of us who experience constant fatigue. Fatigue is always there and only varies in intensity. The biggest challenge is how to structure our day so that small achievements are possible without compromising oneself. Some people have little control over fatigue, no matter what they do. It becomes a matter of learning how best to live with it. Knowing and identifying triggers for fatigue (if there are any) assists us to attain some sense of control and confidence. If we know what triggers fatigue we can avoid or minimise these events or situations where possible. For all of us, having learnt what helps to alleviate fatigue enables us to know what we need to do should fatigue emerge in our day. We now discuss what we have learnt to be the triggers for fatigue.

### *Are there triggers for your fatigue?*

I have not found any triggers. The fatigue survives completely on its own power.

*Graham*

A flare up of my crohn's colitis triggers my fatigue. I can become tired with a restless night or having done too much, but it is not the same as the deep fatigue from my illness.

*Di*

Although fatigue is a constant part of my life, certain things will make it worse and less manageable. Sometimes just pushing myself too hard or overdoing things, seem to be obvious triggers. Emotional stresses trigger my fatigue just as easily as physical stresses, but these are often harder to avoid, so controlling the resulting fatigue is more difficult. At other times there are no obvious triggers. Extreme fatigue may suddenly hit for no apparent reason, especially late in the day or evening. Some days it's all I can do to get out of bed and the day is full of overwhelming fatigue, though I can think of no obvious cause." Triggering factors are trying to do too much, stress, family problems, and health.

*Chrispy*

No - I suffer fatigue 24 hours a day, however some things will make it worse...just the progression of the day and any exercise or overactivity. The fatigue I suffer is an accumulation of the fatigue from the cancer, the cancer treatment, the encephalitis, the pituitary tumour and the fibromyalgia. It's more than normal for any sufferers of these diseases because of the cumulative effect... it's basically 'layer upon layer' of fatigue.

*Iolanda*

Stress is a big trigger for me, which suggests that a lot of the fatigue I feel is emotional rather than physical. In this case, exercise can actually help.

*Andrew*

If I do too much for a couple of days running it can bring on a bout of fatigue. I also find that sleeping really badly is a product of my fatigue not the other way around.

*Michelle*

Overdoing it seems to be the main trigger for me. This is particularly so if I have had a good day with a bit of energy. Then I rush around and try to do too much, not only housework. I also overdo it on the quilting side too. Sometimes I get a bout of fatigue for no apparent reason. Whatever causes the fatigue it just has to be endured.

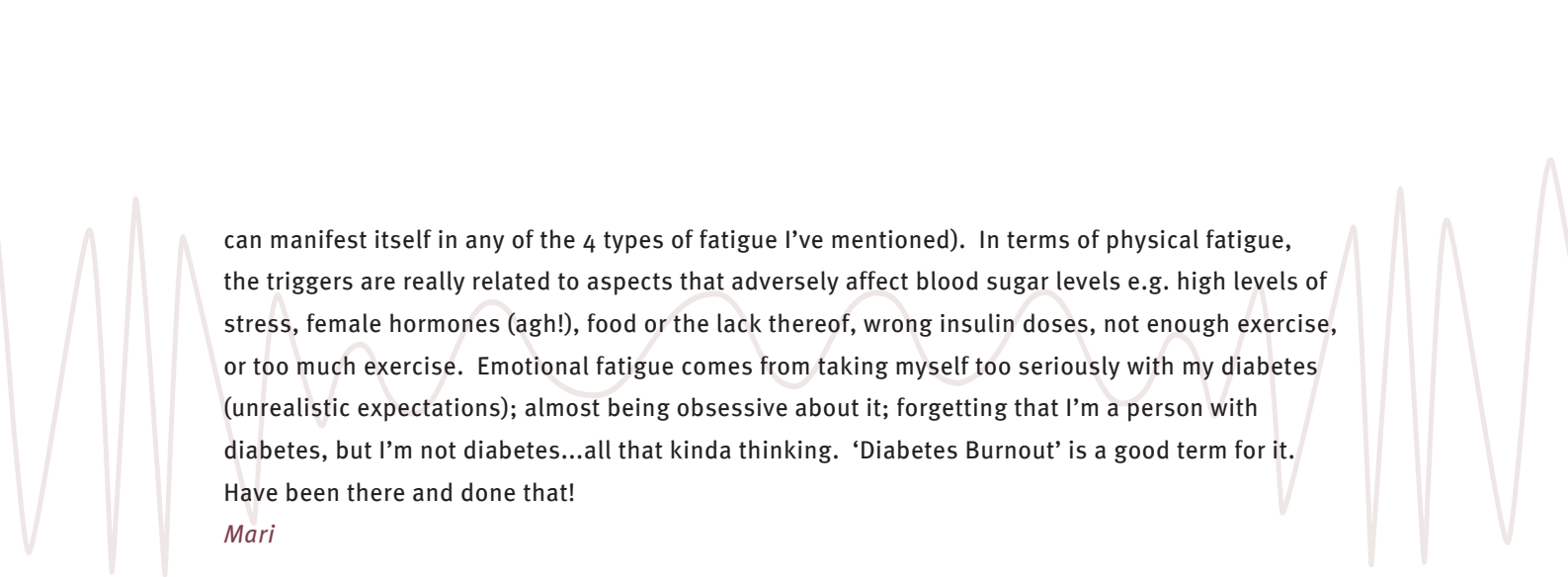
*Helen*

The biggest trigger for me is over-commitment. By this I mean that I get enthusiastic about "doing" when I am having a good day. I momentarily forget that I have limitations i.e. a chronic illness that slows me down and demands necessary levels of attention. So I extend myself too far in giving to others, or doing too much in one day etc. It leaves me exhausted (and



**INSULIN**

Each drop is a lifeline for my being  
Every cell yearns in deficit  
Yet agitates in excess  
They thrive on balance  
Just like the rest of me  
– Mari



can manifest itself in any of the 4 types of fatigue I've mentioned). In terms of physical fatigue, the triggers are really related to aspects that adversely affect blood sugar levels e.g. high levels of stress, female hormones (agh!), food or the lack thereof, wrong insulin doses, not enough exercise, or too much exercise. Emotional fatigue comes from taking myself too seriously with my diabetes (unrealistic expectations); almost being obsessive about it; forgetting that I'm a person with diabetes, but I'm not diabetes...all that kinda thinking. 'Diabetes Burnout' is a good term for it. Have been there and done that!

*Mari*

Over doing it. Consciously pushing through, not hearing my mind and body's call for rest and peace, fullness. Being a glutton and wanting everything I can manage without any real connection to the self.

*Olympia*

## Managing Daily Life

Living with fatigue is complex, but the approach to incorporating it into our lives may be straightforward. If we learn how to respond to fatigue in constructive ways we may feel a reclaiming of a sense of control.

We have learned that we need to plan ahead for activities. It may mean factoring in a period of rest prior to an activity, followed by a period of rest afterwards. Maybe we can organise to have mobility aids or a clear map of where the lifts or toilets are beforehand to minimise effort during the outing. Educating significant people in your life about your needs to relation to fatigue may assist them to be understanding and supportive. Attaining a balance of rest and activity seems to be important. Learning your own particular requirements for rest enables a pattern for living which shapes each day.

It may be helpful to reorganise the home to enable conservation of energy. Examples include reorganising cupboards so that things are easily accessible, or having a stool in the kitchen or bathroom to reduce the need to stand. Some of us who are fatigued constantly may need more bed rest. Sitting takes less energy than standing. Lying flat with your body and mind at rest appears to reduce the effects of fatigue for some people. If employed, then consider opportunities to negotiate hours of work to minimise fatigue. For example, working shorter hours in each day or having a longer period of rest in the middle of the day, having somewhere you can lay down at work and using a wheelchair if mobility is an issue, can making working possible.

The unpredictable nature of fatigue means that we become flexible and ready to change plans when necessary. Guilt about sudden changes of plan only burdens us emotionally. We consider it part of looking after ourselves to communicate to others about fatigue. It is vital to our sense of self to be

achieving something each day, despite fatigue. So, setting small tasks or projects so that we feel a sense of purpose and pleasure in our day is important. It can provide balance to the times when we need to rest and helps us to feel good about ourselves. We talked about how we adapt our lives to incorporate fatigue.

### *How do you adapt for fatigue in your day to day life?*

I try to make certain I do something each day, but I only do small things. It takes my determination to overcome the effects of fatigue. In the long term this does take its toll on me in mental stress and strain.

*Graham*

If the fatigue is overwhelming, I rest, sit on a chair for a long time without doing anything, and try to do just the basic tasks like eating something when needed, not cooking much, having a shower maybe, accepting that I can't do anything about it and cancelling any outings. If it is fatigue that I can manage I try to do whatever was planned but don't drive or attend any outings where I might be expected to be chatty and sociable, or be active.

*Di*

I sleep nearly 40% of my life away, but this doesn't eliminate the constant fatigue, rather it helps me cope with it. I try to pace myself in order to control my level of fatigue and have limited success. Life simply doesn't allow me to completely plan out what I think I will be able to do without worsening fatigue. Imposing limits on both the type and amount of activity or social event, is one way I try to manage fatigue. Again I have limited success, as sometimes fatigue appears as a sudden crushing force, which is unavoidable and unstoppable. I find I'm increasingly avoiding such situations, as sudden overwhelming fatigue may quickly turn into an adrenal crash, taking days to recover. These are debilitating and humiliating events, which I try to sleep off, but avoiding social events in particular, leads to social isolation. When this happens, my husband tells me to "roll with it and not fight it." This is hard but when I can do so, extreme fatigue is more manageable and recovery a little faster.

*Chrispy*

By limiting the amount I do each day and taking care of myself by relaxing in between jobs. Going to bed early to recuperate for the next day.

*Ted*

I have to basically work around the things I've got planned. So for every activity out of the house, I have to rest the day before going out, and recover the day after. If I do go out, I have to leave early, even after only 1 hour, because I can't stay longer. I've missed weddings because I haven't had enough energy to even attend the church service.

*Iolanda*

Remain active (when you can) as it really does help. As I start early in the morning, I am in bed by 9:30-10:00 at night so I get the rest that I need. If I need to, I have a snooze for a while when I get home from work. I also have arrangements at work to be able to take a nap if I need to. There is a time to give in to fatigue and time to fight it off - we need to know the difference.

*Michelle*

By planning everything that you do, not just for that day but for the whole week sometimes. By realising sometimes that you are overdoing it and so I cut back on what I'm doing or take time out to rest.

*Andrew*

Learning to accept fatigue as part of my life. I don't think this is defeatist, more realistic. Learning to "give in" when necessary, to sleep late, go to bed early etc. without feeling guilty. This is made easier with an understanding and supportive husband and family, both practically and emotionally.

*Helen*

I like to think that I'm getting better at knowing my 'boundaries' - both identifying them for myself and being assertive regarding them with others' expectations. Generally, I like to try to prevent fatigue (easier said than done) by balancing both work and play, and eating and exercising. Managing stress is a huge one...I try to find at least one pleasurable thing to do each day.

*Mari*

Take it slower, ask for assistance, restructured my work life, avoid back to back activities, early nights, good diet /exercise, meditative rituals.

*Olympia*

## Explaining Fatigue

The experience of fatigue may not be easy for others to understand, hence it may be misinterpreted as laziness or lack of motivation. The experience of repeatedly attempting to get others to understand about fatigue may lead to thinking that it is futile to try to explain. Lack of understanding and unhelpful, simplistic suggestions for remedies can frustrate us. We have developed more readily accepted excuses for not being able to do things because of fatigue, such as "I am not feeling well" or "I am in pain". These responses can avoid unwanted reactions arising from misunderstanding about fatigue.

The experience of fatigue sometimes does not hold legitimacy in the eyes of others. Most of us feel that it is important that some people, family and close friends are aware of, and understand, fatigue so that they do not misinterpret our actions or inability to participate. We are selective

about who we talk to about fatigue and have found ways of explaining the experience to those people. Examples centre around attempting to relate fatigue to an experience they are familiar with, such as having a bad case of the flu or thinking of extreme exhaustion, magnified and ever-present. Over time, it may be that the effects of fatigue become evident to others and a level of understanding builds up about what is happening, making explanations less necessary.

While health workers may not always respond in helpful ways when we raise fatigue issues, it is important to persist in relaying the experience and impact of fatigue. Fatigue is part of the condition or illness we are living with, hence it becomes part of our lives, and it is important that we make health workers aware of its presence. We discussed our experiences of communicating to others about fatigue.

### *How do you communicate with others about fatigue?*

I have given up trying to explain it to others. The blank looks and obvious responses such as ‘take a tonic’ or ‘rest up and you will be fine’, become just too depressing. The best way that has occasionally worked is that I feel like I have a really bad case of flu.

*Graham*

I don’t communicate about fatigue much because unless someone has experienced it, they simply cannot understand it. I avoid some outings; hide the fact that I am so tired although I would be more quiet than usual in company; and if I know people really well I might mention the fatigue but don’t dwell on it. I use avoidance of situations and techniques to hide how I am feeling.

*Di*

Thankfully my husband really “gets it” and understands fatigue, as he suffers it himself. To a lesser degree so do my children and grandchildren. Communicating my fatigue to others who have never really experienced or understood it is not so easy. I’ve come to recognise those who will at least try to understand and may explain how fatigue affects me if necessary. Many people just don’t get it and never will, so trying to communicate it is near impossible. In these instances I no longer waste my breath, but if I need to opt out of something due to fatigue, it’s rare that I mention it. I may simply say I’m not feeling well enough, I’m in pain or that I’m ill and not go into specifics.

I don’t communicate about fatigue much because unless someone has experienced it, they simply cannot understand it.

They can think what they like, but I know trying to explain this invisible fatigue and how it impacts on my life is useless with many people. Although some doctors also just don’t get fatigue, I still try to talk about its effects on my life, as it is a definite part of my condition.

*Chrispy*

## I tell them that I am fatigued and tell them what fatigue means to me.

I just tell people I'm unwell and if they don't like that then that's their problem. I don't feel I should justify that I'm fatigued because of all the disabilities I have. Some people think we are just lazy and don't even try to understand because they can't see any physical reason why we are fatigued. If I'm particularly bad pain wise it affects my gait and then they know why.

*Julie*

I don't have to communicate with people who I've known for the 7 years since being sick, because they already know... they've seen it. But with new people I might mention that I won't be able to stay long, and then they will quickly see in my posture and behaviour that I really am tired and not faking it. I don't really communicate the experience other than if it comes up in conversation. When I'm talking to friends I rarely if ever talk about my health problems and how they've influenced what I've been doing lately. I'll just tell them "what I've been up to". If they ask me how I am I just say "been better, been worse" or "OK". It's a shame that I don't have anybody to talk to about it all, but I don't want the rare phone call I get from friends to be cluttered with problems or complaining on my part.

*Iolanda*

It is important to be able to discuss the impact of our conditions with people - and not only the fatigue aspect. It helps to present it as working out a problem rather than a complaint. So talk about how fatigue affects you, and find ways in which you (together) can manage it. I just tell people straight out that I'm not being lazy and that I'm not just tired. I tell them that I am fatigued and tell them what fatigue means to me. I explain that its like them being really, really tired but magnified about 1000 times and feeling like it 24/7 for sometimes months or even a year at a time.

*Andrew*

It is important that people I see regularly understand how it affects me. It is important that they accept that my absence is due to fatigue not unreliability or lack of interest. Where possible I tend to avoid people who don't understand or accept this. I don't bother with casual acquaintances etc. I just say I'm not well, or something like that.

*Helen*

Being assertive is helpful. I've learned to be transparent (hopefully without whingeing too much...) about the way I'm feeling so it takes the guesswork out of the equation. I like people to know when my functioning is not at a normal level - usually there's a bit of forgiveness there if I behave like an idiot. But on the other hand, I hate to feel 'cocooned' by others on days I actually feel well. The hardest situation comes at work given I do not disclose my own health issues with patients. And sometimes the last thing I feel like doing is seeing them when I'm feeling unwell myself.

*Mari*

I talk and share the experience, I yell, I close myself away, I disconnect from the world.

*Olympia*

## Telling It Like It Is

We may feel isolated from others because they do not understand or support us with fatigue. Since fatigue is commonly experienced, and for some of us constant, this can be a heavy burden. The lack of understanding or acknowledgement of fatigue impacts on the way we feel about our self and our identity. There is a perceived level of mistrust around the experience of fatigue. As evident in our responses, we are aware of, and sensitive to, other's judgements but feel we have little control over what others think. We talked about what we would like others to know about fatigue.

### ***What do you want others to know about fatigue?***

It exists, rest does not send it away. There is no magic cure.

*Graham*

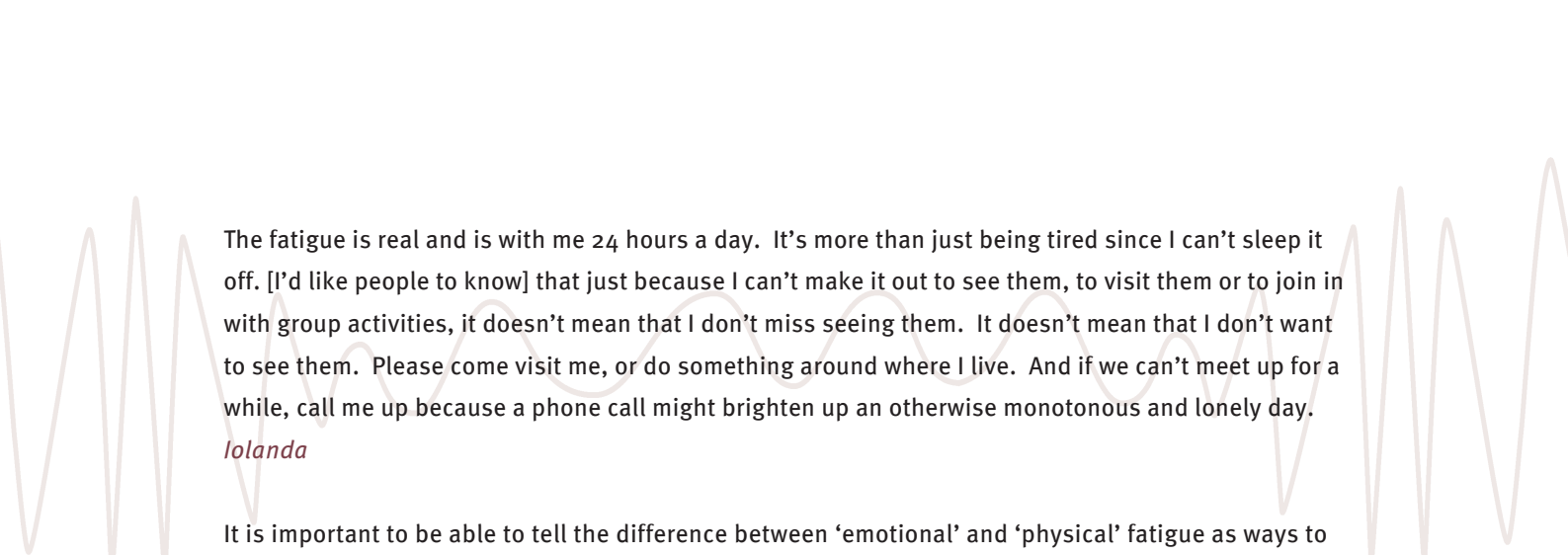
I would like others to know that it is real not imagined. It seems to directly relate to having a chronic illness; that it has not been researched thoroughly so therefore it is not understood by health workers to any extent; that it should be researched thoroughly; it is distinct from just being tired and needing a good night's sleep; that people with fatigue can't just snap out of it; it is not necessarily linked to depression at all; it is not necessarily linked to mental health at all. Fatigue is an energy sapping experience that depletes the body and mind of energy. Sometimes fatigue mounts up and it takes a while to recognise it's impact e.g. finding it hard to be bothered talking a lot; or fussing about anything and also brain fog, can be part of this fatigue.

*Di*

Fatigue is both an invisible and insidious force that can lead to complete and utter exhaustion. Most people with chronic illness will suffer fatigue most of the time, to varying degrees. Other symptoms of illness will exacerbate fatigue. Recognising and accepting fatigue as a part of life, isn't giving in or being weak and useless. Despite what many people may think it certainly isn't all in the head but a real part of everyday life with illness. We need to limit and manage fatigue as best we are able and be willing to "stop" when fatigue gets too much.

I want "normal" people to understand that it is totally out of our control and to wake up to the fact that some things are just unexplainable and to try and have compassion on the things they cannot see or understand.

*Chrispy*



The fatigue is real and is with me 24 hours a day. It's more than just being tired since I can't sleep it off. [I'd like people to know] that just because I can't make it out to see them, to visit them or to join in with group activities, it doesn't mean that I don't miss seeing them. It doesn't mean that I don't want to see them. Please come visit me, or do something around where I live. And if we can't meet up for a while, call me up because a phone call might brighten up an otherwise monotonous and lonely day.

*Iolanda*

It is important to be able to tell the difference between 'emotional' and 'physical' fatigue as ways to deal with them can be different. Getting out and doing something (such as exercise) can help with stress so 'biting the bullet' and doing something CAN actually help. If fatigue is a problem, work out what NEEDS to be done and what would be good to get done. Once everything that NEEDS to be done has been, then you have some flexibility to work around the fatigue. 'Relaxing' or 'Doing nothing' are valid things to put on the list of things to do - we ALL need time to 'recharge our batteries'.

*Michelle*

Having a nap when at work IS valid - although you need to make arrangements with your employer to do this (such as make up the time by working later). Tired people do not work very well so a half hour snooze can allow you to achieve more in the day. Employers are required to make reasonable accommodations for your medical condition - it's a case of working together to find the best overall solution.

*Andrew*

I want others to know that it's not just being lazy or being tired and it's not an excuse to get out of something. Fatigue impacts on every single aspect of your life. It takes immense willpower to even get out of bed most days and that in itself is incredibly draining.

*Iolanda*

I want others to understand that is totally different from being tired; that it is different from "normal" people overdoing it; that a "good night's sleep" won't fix it. I also accept that some people will never understand.

*Helen*

With chronic illness, fatigue is a reality, sometimes a long-term one. It's rarely about just being physically tired. So...Please be gentle but still let me be myself.

*Mari*

That it exists. It's real. Most people living with a chronic illness manage it. Be curious about it, ask about it, talk about it.

*Olympia*

## Brain Fog

One symptom that may or may not be experienced with fatigue has been called brain fog. Typically, our descriptions of brain fog include feelings of disorientation and disturbances to our thinking such as being unable to remember, inability to process information, being unable to think clearly or find words during a conversation. The way brain fog is experienced can vary from person to person. Some of us feel like it is with us all of the time, and others have episodes similar to fatigue. Like fatigue, it is invisible, but may result in an inability to participate in life as fully as we would like. There is little information about brain fog, yet it is another common symptom associated with many chronic illnesses.

Others may not understand about brain fog. It can leave us feeling personally inadequate especially when in a social situation. In a society where intellect is so highly valued, experiences of brain fog are often not understood. When it happens we are vulnerable to others' misguided assumptions and judgements, and we can become sensitive to this. The anxiety about keeping brain fog hidden from others can raise feelings of self-doubt and lowered confidence. We may question our abilities and ourselves. Sometimes we may not have the energy or inclination to keep brain fog hidden but we have learnt not to give ourselves a hard time. Some of us have developed humorous ways of coping with brain fog. These include collecting brain fog stories to share with others and developing humorous ways of explaining brain fog in the presence of others. A favourite way of explaining relates to the analogy of a malfunctioning computer. We wanted to share some examples that may be useful to you.

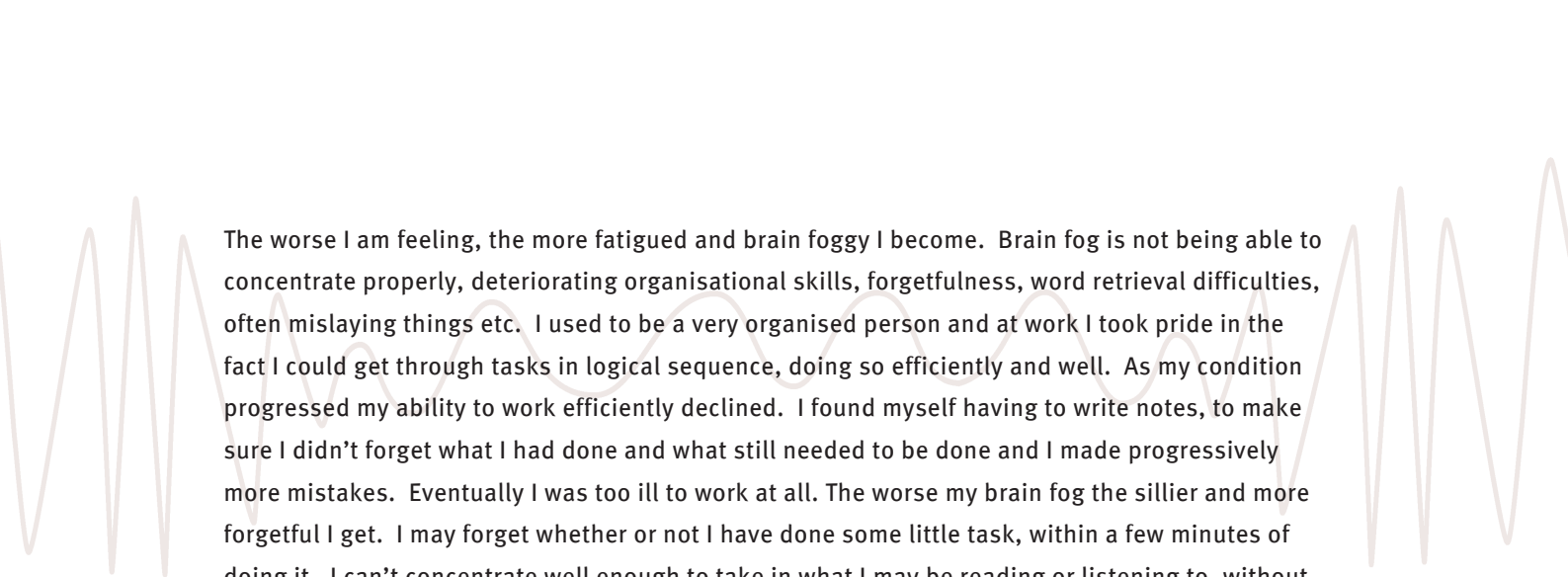
- 'sorry, I'm suffering from the mental equivalent of a computer virus and it's deleted all the files on my brain's hard drive. I can't get anything in or get anything out!!'
- 'ummm....my files have performed an illegal operation and need to be shut down....(lots of laughs)'
- 'I'll have to shut down as I'm suffering complete system overload.'
- 'My brain's anti-virus scanner couldn't detect the latest worm virus, which has completely infected both my input and output functions.'
- 'My brain doesn't have enough memory chips to make the necessary downloads.'

We had many conversations about brain fog.

### *What is your experience of brain fog?*

... brain fog is something I contend with daily. It is hard to determine the cause of the fog, it could be from fatigue, or lack of sleep or something all on its own. The fog makes it hard to think straight and if by chance you get a thought, it is hard to make it a coherent one, let alone convey it to others.

*Graham*



The worse I am feeling, the more fatigued and brain foggy I become. Brain fog is not being able to concentrate properly, deteriorating organisational skills, forgetfulness, word retrieval difficulties, often mislaying things etc. I used to be a very organised person and at work I took pride in the fact I could get through tasks in logical sequence, doing so efficiently and well. As my condition progressed my ability to work efficiently declined. I found myself having to write notes, to make sure I didn't forget what I had done and what still needed to be done and I made progressively more mistakes. Eventually I was too ill to work at all. The worse my brain fog the sillier and more forgetful I get. I may forget whether or not I have done some little task, within a few minutes of doing it. I can't concentrate well enough to take in what I may be reading or listening to, without rereading it several times or asking people to repeat what they just said. If I am responding to messages on the computer, it may take me twice as long as usual and I'll make many dyslexic type mistakes. I have trouble expressing myself and often can't find the words or names I'm looking for. I tend to forget where I've put things, sometimes taking days to discover an object's whereabouts. Through Internet support groups I've found that "brain fog" for want of a better term, is very common among people suffering chronic illness. By sharing our brain fog experiences, I no longer feel alone with this affliction and can see the funny side of these little lapses. I've actually started collecting brain fog stories and when I have enough, I'll share them with other members. Silly things like spending 10 minutes searching everywhere for my bright purple rubber gloves, only to discover I was wearing them all the time or the time I accidentally sprayed my husband with oven cleaner instead of insect repellent as they were in similar coloured pressure pack cans. Humour is an excellent way in helping to cope with brain fog.

*Chrispy*

To describe the way I actually feel with brain fog is slightly disoriented, a tad slower to think through things sometimes (as many people are when they are just tired or running around after toddlers all day), perhaps not able to juggle lots of different activities and thoughts all at the same time, not able to concentrate for lengthy periods or staring at the computer screen or reading and my memory seems to work slightly differently. Also, it is somehow linked at times to fatigue and can be linked to having eaten food that does not agree with me.

*Di*

I have 'word retrieval' problems particularly if I am tired, fatigued or if about a specific topic where I have to remember more sharply, and I feel as if my brain is searching. So I have to stop trying to think of the word and sometimes it just floats into my mind after a few minutes or sometimes it could be hours later. I find also that my brain sometimes finds a word that sounds the same but does not have the same meaning, my poor ol' brain must have become desperate. It can be very frustrating if you want to have a really good conversation with someone about something. I find often people don't want to talk about anything too 'deep and meaningful'.

I think 'self doubt' comes from 1) not wanting to be seen as foggy by others AND more importantly, (2) also because it threatens in some way, independence, being able to cope and look after oneself. Also 'self doubt' makes you question yourself - is it brain fog? Does everyone else do this sometimes i.e. people who are not ill? Have you lost the plot? Were you always like this and hadn't noticed and so it's normal?? Does it mean you will forget really serious things? Maybe it doesn't mean anything? Is my illness anything to do with it or is it happening anyway? The 'self doubt' jars your self-confidence a little and makes you feel a little unsure of yourself. That's how I feel and they are the sort of things I think about.

*Helen*

Brain fog is a classic symptom of Fibromyalgia that I also have. Its also a classic symptom of many other syndromes or chronic pain. I do know that if I haven't had my B12 injection my coordination skyrockets out of control and I can't put one foot in front of the other, my brain just can't work it out. Same as forgetting where I put my glasses, what I went to the shops for, where am I going, dropping things, not remembering if I've actually used shampoo or if I am about to use it, forgetting what I was going to say next, the list goes on, forgetting if I've locked the door even though I just locked it, same as turning off the heater. Struggling to react appropriately to everyday situations is a constant effort which adds to our stress levels thereby causing other problems with our bodies because they break down under the constant stress.

*Julie*

Brain fog is frustration! It's knowing exactly what you want to say or the particular word that you are trying to say and it just won't come out. You have it in your head, you can picture it, but the signal from the brain to the mouth misfires and nothing happens. It's about not remembering what you are/were doing or why you are going somewhere. It's constantly repeating yourself because you don't remember that you have told that person the same thing over and over again. It's frustration and fatigue and anger all rolled into one. It's not being able to absorb what you are reading no matter how many times you read it. It's getting sidetracked from what you were/are doing so easily. Not being able to have clear thoughts. Feeling foggy and muddled.

*Michelle*

Been experiencing it this morning - can only think about one thing at a time and generally have a bit of a short fuse (particularly if interrupted). I also don't feel like doing that much either, or more accurately, I want to do things but don't really feel like making the

Brain fog is the feeling I have when I want to connect with everyday life, conversations, thought processes etc, but it seems like I'm separate from the real experience.

effort. What helps me to deal with it is to be able to do something with the hands, some light gardening or similar which keeps one occupied but doesn't need the brain to be engaged.

*Andrew*

I was thinking and referring to the self doubt that comes with a conscious awareness of my own fogginess, like the lack of clarity, the slowness of thought and processing although I can see it working in the opposite direction also. Although when I'm foggy I don't think I have the capacity or energy to think how do I keep this fogginess to myself.

*Olympia*

Brain fog is the feeling I have when I want to connect with everyday life, conversations, thought processes etc, but it seems like I'm separate from the real experience. It's a dull or cloudy sensation where I lose concentration, become absent-minded and can't 'join the dots'. I've taken out insurance on my purse, keys, mobile phone etc, because I tend to lose them in brain fog moments. There's also a peculiar sense of slowness both in my physical capacity to do things and in my cognition. I mostly experience brain fog with blood sugar extremes (low or high) or severe fluctuations between the two. Sometimes I also experience brain fog when I'm feeling overwhelmed with life and subsequently have no threshold to deal with any more 'reality'. It is almost like a safety mechanism that steps in when my being has reached saturation and cannot process anything else.

*Mari*

### **"Spoons Story" A description of Chronic Illness (author unknown)**

My best friend Jenni and I were in the cafe talking. As I went to take some of my medicine with a snack as I usually did, she watched me this time, with a kind of stare, instead of continuing the conversation. She then asked me out of the blue what it felt like to have Lupus and be sick. I was shocked not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. Jenni had seen me cry in pain, what else was there to know? I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what it felt like, not physically, but what it felt like to be me, to be sick.

As I tried to gain my composure, I glanced around the table for help or guidance, or at least stall for time to think. I was trying to find the right words. How do I answer a question I never was able to answer for myself? How do I explain every detail of every day being affected, and give the emotions a sick person goes through with clarity. I could have given up, cracked a joke like I usually do, and changed the subject, but I remember thinking "if I don't try to explain this, how could I ever expect her to understand. If I can't explain this to my best friend, how could I explain my world to anyone else?" I had to at least try.

At that moment, the spoon theory was born. I quickly grabbed every spoon on the table; hell I grabbed spoons off of the other tables. I looked at her in the eyes and said "Jenni, here you go, you have Lupus". She looked at me slightly confused, as anyone would when they are being handed a bouquet of spoons. The cold metal spoons clanked in my hands as I grouped them together and shoved them into her hands. I explained that the difference in being sick and being healthy is having to make choices, or to consciously think about things when the rest of the world doesn't have to. The healthy have the luxury of choice; a gift most people take for granted.

Most people start the day with an unlimited amount of possibilities, and energy to do whatever they desire, especially young people. For the most part, they do not need to worry about the effects of their actions. So, for my explanation, I used spoons to convey this point. I wanted something for her to actually hold, for me to then take away, since most people who get sick feel a "loss" of a life they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case Lupus, being in control.

I asked her to count her spoons. She asked why, and I explained that when you are healthy you expect to have a never-ending supply of "spoons". But when you have to now plan your day, you need to know exactly how many "spoons" you are starting with. It doesn't guarantee that you might not lose some along the way, but at least it helps to know where you are starting. She counted out 12 spoons. She laughed and said she wanted more. I said no, and I knew right away that this little game would work, when she looked disappointed, and we hadn't even started yet. I've wanted more "spoons" for years and haven't found a way yet to get more, why should she? I also told her to always be conscious of how many she had, and not to drop them because she can never forget she has Lupus.

I asked her to list off the tasks of her day, including the most simple. As she rattled off daily chores, or just fun things to do, I explained how each one would cost her a spoon. When she jumped right into getting ready for work as her first task of the morning, I cut her off and took away a spoon. I practically jumped down her throat. I said "No! You don't just get up. You have to crack open your eyes, and then realise you are late. You didn't sleep well the night before. You have to crawl out of bed, and then you have to make yourself something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today and tomorrow too." I quickly took away a spoon and she realised she hasn't even gotten dressed yet. Showering cost her a spoon, just for washing her hair and shaving her legs. Reaching high and low that early in the morning could actually cost more than one spoon, but I figured I would give her a break; I didn't want to scare her right away. Getting dressed was worth another spoon. I stopped her and broke down every task to show her how every little detail needs to be thought about. You cannot simply just throw clothes on when you are sick. I explained that I have to see what clothes I can physically put on if my hands hurt that day buttons are out of the question. If I have bruises that day, I need to wear long sleeves, and if I have a fever I need a sweater to stay warm and so on. If my hair is falling out I need to spend more time to look presentable, and then you need to factor in another 5 minutes for feeling badly that it took you 2 hours to do all this.

I think she was starting to understand when she theoretically didn't even get to work, and she was left with 6 spoons. I then explained to her that she needed to choose the rest of her day wisely, since when your "spoons" are gone, they are gone. Sometimes you can borrow against tomorrow's "spoons", but just think how hard tomorrow will be with less "spoons". I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So you do not want to run low on "spoons", because you never know when you truly will need them. I didn't want to depress her, but I needed to be realistic, and unfortunately being prepared for the worst is part of a real day for me.

We went through the rest of the day, and she slowly learned that skipping lunch would cost her a spoon, as well as standing on a train, or even typing at her computer too long. She was forced to make choices and think about things differently. Hypothetically, she had to choose not to run errands, so that she could eat dinner that night.

When we got to the end of her pretend day, she said she was hungry. I summarised that she had to eat dinner but she only had one spoon left. If she cooked, she wouldn't have enough energy to clean the pots. If she went out for dinner, she might be too tired to drive home safely. Then I also explained, that I didn't even bother to add into this game, that she was so nauseous, that cooking was probably out of the question anyway. So she decided to make soup, it was easy. I then said it is only 7pm, you have the rest of the night but maybe end up with one spoon, so you can do something fun, or clean your apartment, or do chores, but you can't do it all.

I rarely see Jenni emotional, so when I saw her upset I knew maybe I was getting through to her. I didn't want my friend to be upset, but at the same time I was happy to think finally maybe someone understood me a little bit. She had tears in her eyes and asked quietly "Christine, How do you do it? Do you really do this everyday?" I explained that some days were worse than others; some days I have more spoons than most. But I can never make it go away and I can't forget about it, I always have to think about it. I handed her a spoon I had been holding in reserve. I said simply, "Jenni, I have learned to live life with an extra spoon in my pocket, in reserve. You need to always be prepared"

## Our Message To You

Your own awareness of fatigue and the activities, or the level of activity that can trigger fatigue are important in managing its impact in your life. If you can identify what might make fatigue worse for you, your daily activities may be adapted to minimise the impact. Some ideas are:

- It is usual to feel cranky, sad, angry, and frustrated with an illness that causes extreme fatigue but if you feel this way over a period of time, let a health worker know because you may need help with depression.
- Use trial and error to find if the fatigue you experience has triggers. A daily diary maintained over a period of time might help you find triggers.
- Divide a big task into smaller ones. Allow yourself more time to complete things.
- Prioritise tasks so you decide those that are essential and those that can wait.
- Save some energy for things that bring you pleasure.
- Listen to and learn to trust your body. Rest when your body signals it needs it.
- Learn ways to enjoy restful periods and to nurture yourself with favourite music.
- Try avoiding heavy meals, alcohol, caffeine, and large quantities of junk food.
- If it is possible for you, consider maintaining a level of activity and exercise.
- Talk with trusted others about how fatigue affects you so you may gain their understanding.
- Seek support groups either in your community or through the Internet.
- Focus on your achievements and strengths.
- Use humour when you can.
- If you feel your health worker is not taking fatigue seriously, consider seeking a second opinion.

## Our Message To Health Workers

Fatigue is real and can have a profound impact upon people's lives. When it strikes it can trigger and compound feelings of worthlessness and inadequacy. It can emphasise the loss of control that people experience when living with chronic illness and trigger old grief emotions. For some it is the most difficult symptom to manage. People often feel misunderstood about how fatigue affects them. Listen carefully when people with chronic illness describe their experiences of fatigue and affirm their story. They will be looking for signs of your reaction and beliefs about fatigue. Take fatigue seriously. Consider obtaining a medication review or if there is presence of infection or other aetiology that may be contributing to the exacerbation of fatigue. Knowledge of resources and groups within their community may be helpful. Consider talking with people about some of the suggestions we have made in the section above.

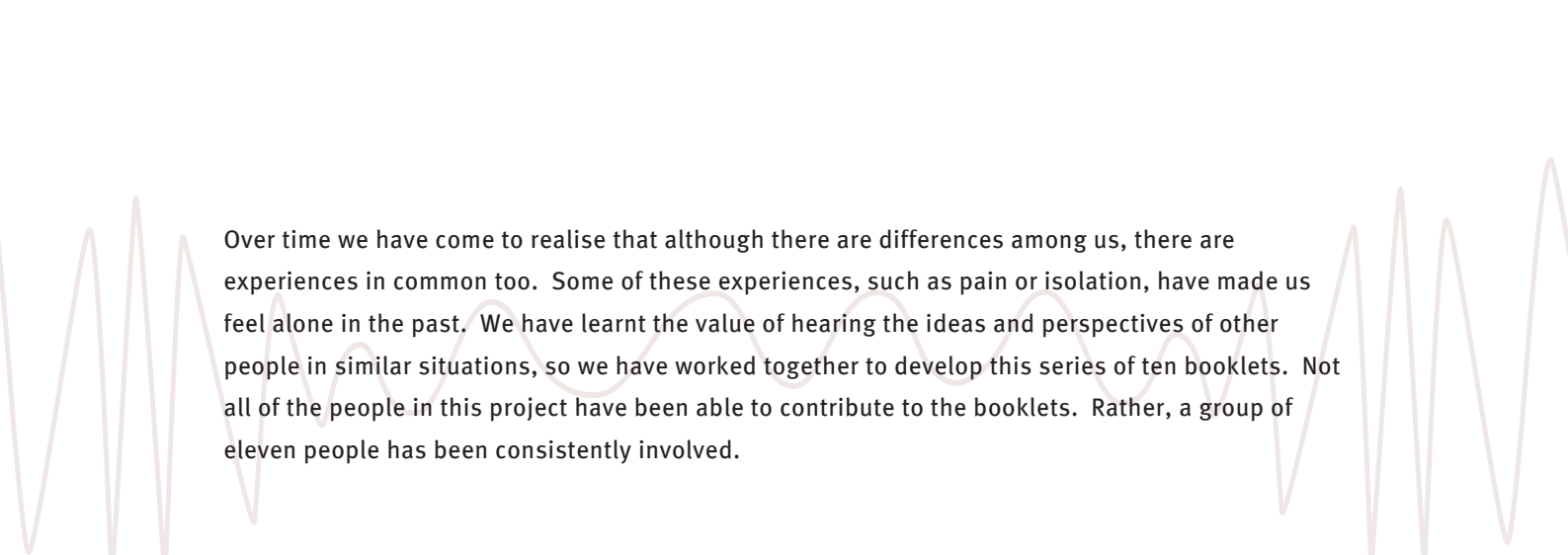
## About Us

We are men and women who live with chronic illness. Our ages, sexuality, backgrounds and economic situations are diverse and these all impact on the way we experience illness. We are participants in an Australian research project that connects people living with long term illness through the Internet. Talking with each other on the Internet facilitates an opportunity to discuss issues related to our experience. We came together through being involved in a research project. Over time we have got to know each other through our email conversations. We feel strongly connected to a network of caring and support that carries us through the hard times and enables us to celebrate each other's good times. Knowing that we can always tap into the understanding and support of others who live with chronic conditions is important in our approach to making sense of, and managing illness.

There has been a lot of discussion about chronic illness self-management promoted by health care professionals. Yet it has been estimated that between 95 percent and 99 percent of chronic illness care is given by the person who has the illness. In other words, we look after ourselves. On a day-to-day basis we are in charge of our own health, and the daily decisions we make impact upon our quality of life.

We all have something in common: we live with a chronic illness. A chronic illness is one that persists over time without an easily definable beginning, middle and end. While the symptoms that accompany a chronic illness can usually be alleviated to some extent, the illness itself is not curable. What we share is that illness was an unexpected intrusion into our lives.

Living with chronic illness brings many life issues to the fore. One of the primary experiences for us has been the realisation that our lives have changed, often permanently. Illness has disrupted our future plans. It has troubled our partners, family and friends when they realise the way in which illness has intruded on our collective lives. However, we are learning to deal with the many changes that the illness has brought to our lives.



Over time we have come to realise that although there are differences among us, there are experiences in common too. Some of these experiences, such as pain or isolation, have made us feel alone in the past. We have learnt the value of hearing the ideas and perspectives of other people in similar situations, so we have worked together to develop this series of ten booklets. Not all of the people in this project have been able to contribute to the booklets. Rather, a group of eleven people has been consistently involved.

## About The Booklets

We decided to share our experiences in a series of eleven booklets. The purpose of these booklets is to share some of our conversations about many interesting and difficult aspects of living with illness. Our conversations have been a safe place where we can seek understanding and support as we tackle the issues that confront us physically, emotionally, socially and spiritually. We are supporting each other by sharing information, emotional comfort and friendship. In these booklets we share our discussions.

The booklets are set out in question and answer format and are intended to connect you with our voices about our experience of living with long term illness. There are no right or wrong answers to these questions. Our answers reflect our current thinking and understanding about what it means to live with long term illness. Maybe you will find some experiences and ideas that are familiar to you or have meaning in the context of your life. We acknowledge that challenges are part of life and fall within the experience of all human beings. Given this, our experiences may also be helpful to people living without illness.

## About The Research Inquiry

A three year research grant (2003-2006) from the Australian Research Council (ARC) was awarded to our research team. This was a collaborative project between The University of South Australia and the Research Unit, Royal District Nursing Service. The investigators are Professor Tina Koch, Dr Debbie Kralik and Dr Kay Price. Project Management Members are Kerry Telford, Professor Jim Warren, Gino Pignone and Natalie Howard.

## What Are We Researching?

The main thrust of the research program has been to understand the ways that people make transitions or learn to live well with chronic illness. We are interested in ways that people can learn to incorporate the consequences of chronic illness into their lives and move on. How people learn to move on or make transitions is important to understand, and so this project aims to describe this transition.

