

PERSONAL RELATIONSHIPS
INTIMACY AND ME/CFS

Dr Lisa Dvorjetz
Advisory Psychologist
to the ME Association

**WARNING:
CONTAINS ADULT CONTENT**



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WHAT DO WE MEAN BY INTIMACY?
IS IT IMPORTANT?
WHO CAN WE TURN TO FOR HELP?
INTIMACY COMES IN MANY FORMS...

In this leaflet we feature several stories from people with ME/CFS who are or were in relationships and who describe how they managed to cope with intimacy.

Since we published the initial article from Fiona and her husband Matt in the Spring 2021 issue of ME Essential Magazine, we have received a lot of positive feedback, and some of this is also reflected below.

Intimacy among those who are disabled by ME/CFS can be challenging, and it can be just as difficult to talk and to write about.



But personal relationships are an important issue and it is something that the ME Association has been asked to feature by those in the community.

We hope that by reading these honest accounts and discussing these issues, it will help other couples who are facing the same or similar concerns.



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INTRODUCTION

All humans have a fundamental need to feel connected to and build intimate relationships with others. The diagnosis of a chronic health condition can severely impact the way we view ourselves as well as how we relate to our partners and loved ones.

One of the many challenges that relationships face when one of them has a long-term illness is 'how can I be looked after as well as experience sexuality?' From the partner's perspective, 'how can I look after my loved one whilst also having my sexual needs met?' Our relationship to our body and body image changes as we start to make sense of the impact that a physical condition has on our wider sense of self. Through these changes we may experience a range of emotions such as uncertainty, pain, numbness, fear, sadness, loss, anger, hurt, guilt and shame amongst others. How we respond to such emotions can have a consequence on our relationship as it can either allow us to open up conversations with our partner(s) to reach for intimacy or conversely to pull away and disconnect.



Intimacy and how we feel when being intimate is a very personal experience that includes our sexual, emotional, physical and spiritual selves. The way that we view intimacy is largely impacted by

wider cultural factors such as our awareness of gender roles, race, religion, class, age, sexual orientation, ethnicity and family narratives. Sex and intimacy are often viewed together but they are separate experiences, which means that we can have intimacy without having sexual intercourse. While sexual intercourse is defined as a specific type of action, intimacy is different and speaks to the way we individually connect to others. If we are able to see sex and intimacy through the lens of establishing a meaningful connection rather than a goal-orientated outcome, we are able to eliminate some of the underlying pressure that people can sometimes feel when it comes to sex.



The introduction to **Personal Relationships, Intimacy and ME/CFS** was written by Dr Lisa Dvorjetz, Advisory Psychologist to the ME Association.

Dr Lisa Dvorjetz is an accredited counselling psychologist with both the British Psychological Society and the Health and Care Professions Council.

Lisa is currently working within the NHS and private practice with people who have long-term health conditions.

We know her well.

She has been volunteering as an ME Connect helpline supervisor since 2013.

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Often a lot of these aspects are unvoiced as we enter into relationships. However, when a health condition is diagnosed and impacts on the relationship, it can encourage us to explore the assumptions and expectations that we may have had of ourselves and the other. We can ask ourselves questions like 'What's important when being with my partner(s)?' or 'What's important to us as a couple/relationship group?'

Just as the experience of intimacy is a very personal one, people's experience of ME/CFS is also be unique to them and their relationship. As we will read about in this leaflet, some members of the ME/CFS community have spoken about the impact that pain, energy levels, physical disability and emotional wellbeing have had on their sense of who they are as sexual beings.

In our work with people who have ME/CFS, we have found a number of ways to keep intimacy strong in the face of the chronic health condition. These few points for reflection may help you to think about what's important to you and how to express them in your relationship.

1 Communication – find a time when you can either reflect on your own or open up a dialogue with your partner(s) about your intimate relationship. What has changed? What would you like to be different? How can you have your needs met as well as meeting the needs of your partner(s)? How can you keep checking in with yourself and your relationship when it comes to sex?

2 Exploring adjustment – with a chronic illness that can present itself in unpredictable ways, this will mean that you may be constantly having to go through a process of adjustment and loss. What physically or emotionally do we need to do differently? How do you both cope with and support the other(s) in the unpredictability of life? How do changes in intimacy impact on your identity as a woman or man?

3 Finding balance – both your body and your relationship are not static entities and are therefore constantly fluctuating. Find what works best for you and your partner(s). For example, would it help you to create a plan for sex? What did you learn through the process? What would you do differently, if anything, next time? If you only have a certain amount of energy per day, how can you spend it on the things that you value and enjoy? What needs to change?



“My partner is very understanding but I wish I wasn't so exhausted and in pain to be able to enjoy intimacy”

- Helen



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Whether you've recently been diagnosed or have been living with ME/CFS for many years, you may find that you want to seek additional support outside of your relationship to talk about difficulties with sex or intimacy. Counsellors, psychotherapists and psychologists are all trained to help you explore these issues in a confidential space. When seeking a therapist, make sure they are registered with a governing body like the British Association for Counselling and Psychotherapy, British Psychological Society or UK Council for Psychotherapy. For specific sexual and relationship concerns, you may want to seek a therapist from the College of Sexual and Relationship Therapists (COSRT) who can work with you as an individual or with your partner(s).



“Physically it was all too much; it hurt if he touched me. Sex as we knew it had to change...”

- Fiona

FIONA AND MATT'S STORY

FIONA

My name is Fiona, I have suffered with M.E. for 26 years and, for the last 17 years, I have been mainly housebound.

I married the most incredible man, Matt, who has stood by me through thick and thin. I appreciate this is rare and I am incredibly blessed!

My heart goes out to those who have lost partners and loved ones as a result of the illness. Words can't express the devastation of what M.E. can rob from us.

I write with an open heart to share the struggles and the joys, the tears, the pain, and a realistic perspective of how difficult intimacy with M.E. can be.

No one can prepare you for how hard living with M.E. is, let alone trying to balance a relationship and sex with a chronic illness that steals your vitality.

We were married for just a year, before the M.E. hit big time. I was a schoolteacher one day and bedbound the next. For three years I lay spaced out.

Sex? What sex? There is no way that a body that couldn't walk to the bathroom could have sex! Our relationship changed from being lovers to a patient and carer role. At that point I could talk for only five minutes a day – if we were lucky.

Too demanding

We tried to have sex once but the implications were massive for me: another three months of not being able to get out of bed. It was the most excruciating time of relapse.



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Matt didn't like causing so much damage to my body (even though it was a natural thing, and he wasn't actually doing anything wrong).

You don't realise how much your body shuts down when you are ill. Internally, I just felt nothing, it felt like dead wood. My body had shut down on every level with no feelings or sensations.

Physically it was all too much; it hurt if he touched me. Sex as we knew it had to change. Matt was able to relieve himself and he used to draw on my back with his finger to relax me and we classed that as 'sex'.

How we saw 'sex' had completely changed! Sex became him just holding me, holding my hand, lying next to me.

Kissing was hard because my throat was always so sore. But during this time, our friendship grew in depth. We had respect for each other in a very different way.

Pregnancy

After three years of being bedbound, the whole idea of becoming pregnant seemed insane, but we both wanted a family.

We tried and I never would have believed I would get pregnant straight away – and for both of our children!

My body could not do basic stuff so how had it managed to create a baby? It was miraculous.

However, I wasn't able to produce breast milk for either child. I put this down to the body just being too exhausted to make any.

But this caused me to question just how good I might be as a mum, not being able to provide even the basics for my child from my body.

Matt and my mum took on most of the childcare and have helped a great deal in the raising of our children.

I am incredibly grateful to them both. It doesn't feel enough to simply say, 'Thank you'.

Increased intimacy

Twelve years on from having two children, where is the M.E. and how is the sex?

I am still mainly housebound, and my daily activities are very limited. Sex is still very rare as it has huge implications for my body.



“My body could not do basic stuff so how had it managed to create a baby? It was miraculous!”

- Fiona



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It will still render me bedbound for long periods of time afterwards. But it is changing. My body is beginning to feel different; I have started to experience the sensations of sex and to climax. I pray it continues.

Top tip: Lubrication is always handy and helps!

Picking the right time of day to have sex is also vitally important with M.E. I find the morning is so much better than the evening.

There are some bonuses to my husband not being able to travel to work during lockdown. Planning makes a difference too.

I add extra rest before and after to make sure I don't spiral so much. Juggling your energy is key to minimizing the relapses, whilst also allowing you to enjoy intimate time together.

It does take away the spontaneity, but it means the consequences of sex are less significant, so we work with the wisdom we have gained.

Top tip: Stay in tune with your body.

Our bodies are beautifully created, no matter how ill we are, no matter what size, or how we look. We are all created with beauty. So, work with what your body can do and practice acceptance of your limitations within sex.

Adapting sex to M.E.

Some positions are much easier than others. Our bodies are all different. When I am severe, the thought of experimenting with different positions is a no go.

On the rare occasions I have the energy, for me, the ones that work best are those where I can lay on my back which means my body is 'resting' as much as possible. With positions that require me to be on top, my body has not got the strength to take the demands.

If you like to be on all-fours, it can provide a deeper penetration that hits those spots. But, for me, this position is exhausting, so we adapt it and use the bath as a leaning post with Matt standing behind me.

The shower is also a good place for making your love-life a bit spicier. Just kissing and touching each other somewhere other than in bed makes it a little more exciting!

Some positions definitely require more energy, whilst others leave Matt doing all the work.

Honest communication is key. Being able to express how you feel about what is working and what is not really helps.

“We never talk about it. I feel I let him down every single day”

- Peter

I find men might have a different perspective, or maybe it is just me, but the pain takes over any pleasure and certain functions just don't work with the pain levels how they are.

I am in a same sex relationship and sex has just been killed for us four years into marriage. We never talk about it. I feel I let him down every single day.

I lay next to him longing for a hug (just a hug) but knowing I cannot go any further. I do nothing and then I worry, will he find someone else who can give him this?

I know, we need to talk but I have not fulfilled the hopes we had from our marriage and he emigrated to the UK to be with me, I feel so guilty.

It is important that we talk about the issues affecting personal relationships within the community, but I just don't have any answers.

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Having a relationship where you can be honest with each other and where you and your partner have a mutual understanding of the importance of alternating rest and activity is hugely beneficial.

You will find yourselves becoming excellent problem solvers and great time managers! This can also generate much-needed laughter during the process.

Remember that sex doesn't need to revolve around actual intercourse. Manual stimulation and oral sex also provide ways to satisfy each other.

And if you are not in a relationship, a vibrator will also help with reaching your sensitive spots or just provide some gentle pleasure without consuming too much energy – and this helps to reduce the relapse afterwards.

Just because we are ill doesn't mean we can't get creative. We just have to be imaginative in the ways we can express intimacy with one another.

Emotions

It is very hard when you have two people that want to express their love for each other but are unable or limited in how they can achieve it.

You are not free to do the things you would like. Instead, you are restricted, bound by an illness that gives you no break, no real life.

There are days when we just hug and let the tears flow, and there are days we don't understand why or how we have been thrown this curve-ball in life.

Talking and explaining to each other about how you feel is a big key to getting through these times.

We may not feel beautiful or attractive. As a result of being in pyjamas for years, you let your appearance slip. The rawness of the illness leaves us feeling stripped naked emotionally on every level.

Overcoming how we see ourselves and keeping our heads above water is an emotional challenge. Some days it feels like drowning and we just have to hold on to the hope that one day our situation may just change.

I have found myself going through a grieving process. Grieving for the sex missed and grieving for the time together that we could have had.

“Any sex we do
have has to be
carefully planned”

- Stacey

ME/CFS has had a catastrophic effect on my sex life. It's sapped my sex drive as well as making sex physically very difficult.

Any sex we do have has to be carefully planned - it's a form of vigorous exercise and therefore I can't do much afterwards for the rest of the day.

I also can't do it late in the evening as I'm too exhausted, which leaves us with the weekend, and only if we're not doing anything else that day.

I also struggle to enjoy it as I struggle to feel anything, probably due to a combination of ME/CFS symptoms and fatigue, and my lack of libido.

I'm only mildly affected yet it affects my sex life this much. When my ME/CFS was worse, it was just dreadful. I would just be in pain and suffering really bad fatigue throughout, and I would have to rest for a day or two afterwards.

I imagine sex is impossible for those severely affected! I am lucky though as I have a partner who understands, but we both often get frustrated at the state of our sex lives.



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It is hard not to resent your body, get cross with it and hate it for not doing what it should. Mentally it is hard when you want your body to be able to do something that it sadly won't.

I have found there is sometimes a fear of physical intimacy because I know what the demands on my energy will be and what the pain is like afterwards...

As a couple, talking about issues is essential and it does make a difference. I will be honest; these are often raw, painful conversations. Your partner needs a voice and it needs to be heard too.

I struggle with some of Matt's feelings, but I am powerless to change the situation. I am physically unable to change. I am physically dependent on him and it breaks my heart knowing that.

MATT

Being a long-term carer for Fiona means taking on roles I wouldn't necessarily have imagined taking on when starting the relationship.

Fetching, carrying, and performing other tasks because she is unable to, can make me feel more like a servant than a lover.

And providing support and sympathising with the endless list of symptoms and troubles, both physical and emotional, can make me feel like a counsellor rather than stirring feelings of romance.

It can be emasculating and exhausting.

The idea that Fiona is sexually desirable and arousing starts to fade into the background as the needs of the illness and day-to-day living take over; especially after helping her to the toilet for the umpteenth time and listening to her coughing long into the night...

But just because the illness is present doesn't mean that I stop having needs and suppressing those desires and feelings isn't helpful.

Of course, it's completely possible to satisfy my needs with self-gratification methods, particularly when Fiona is not physically able.

The danger here, however, is that the sexual act becomes remote and doesn't involve her. Fulfilling my sexual need by myself can drive a wedge into the relationship and make Fiona feel even less involved.

“No sex leads to low mental health”

- Gemma

I am middle aged, moderate, housebound, unable to work. But sex is an integral part of me. I need it to feel loved and worth something. I'm certainly not capable of being useful in any other way.

No sex leads to very low mental health. We still manage to have sex twice a week on average. Sometimes it can be nine days between times, but then we make up for it another time.

It's not the kind of sex that sets the world on fire, it's simple, and low energy on my part. We make sure it doesn't last too long. But it's needed.

Does it cause a crash? Possibly. Because it happens so regularly it all melds into one. Will I give it up? Absolutely not.

It's the one time I feel human. The one time all pain disappears and the only time I sleep well is after sex. It keeps my marriage alive, stops me JUST feeling like a cared for person and a burden.

My husband is amazing, these are my thoughts, not his. We kiss, cuddle, hold hands, ruffle each other's hair, have many ways of showing intimacy, and we still have sex.

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It is vital to talk about our needs and desires together so we don't lose the romance and sexiness from the relationship.

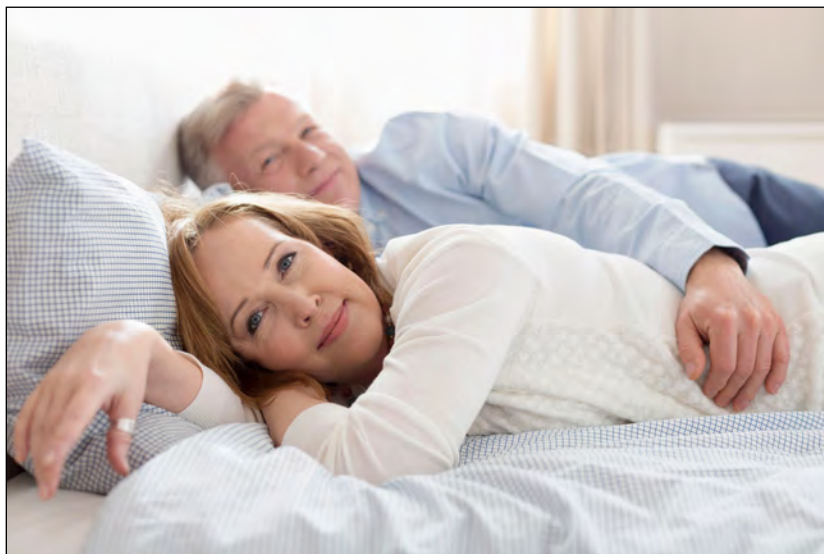
In my experience a disabled partner will likely be quite pleased to learn that you are thinking of them in this way! So why not explore ways that you can express this love together?

You could ask your partner to lie next to you whilst enjoying self-gratification so that, even if they are not able to join in, it is at least something that you can share together.

If Fiona is not well enough to have sex she might touch me instead – less physically demanding for her but an intimacy that reminds us we are not just carer and dependent.

You could ask your partner to wear something lacy and sexy that will arouse desire in you. Explore and talk about ways that you can express physical love within the bounds of the illness and your comfort zones.

You never know what you might discover and it might bring you closer together.



“My husband hates coming home”

- Rosa

I can relate so well with Fiona and Matt. I've had ME for 26 years and was a teacher before getting pneumonia, then ME.

However, I haven't been able to discuss much about intimacy as my husband just doesn't want to.

We have been married for 26 years, then he suddenly said the most hurtful things, like I would be better off dead as I had no quality of life. If it were him, he said, he would have killed himself by now.

He was happy when out on his bike or hiking but absolutely hated coming home.

I'm really not well enough for sex but also he never sits near me. I lie on my bed in the living room and he sits on the sofa. All we do together is watch TV for as long as I can manage in the evening.

For me, he has crossed that invisible line. I wanted him to leave but I realise that I can't manage alone. He also doesn't want to leave, but this is because he has nowhere to go.

I've become a very good actress. I'm living with a stranger in a very odd and stressful situation but I also feel very guilty because I now feel like I'm using him.



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JOANNA'S STORY

I read the article, 'Personal Relationships: Intimacy and ME/CFS' and by the end of it tears were pouring from my eyes.

It is so honest and absolutely spot on. I had been single, and suffering from ME for many, many years when I met the man who is now my husband.

I think the disease has robbed me in terms of how I see myself as a woman. Before I was ill, I had a busy career and loved looking my best and taking care of myself.

For women, I think looking good and feeling attractive is linked to your libido. When looking good means having clean hair and a fresh nightie on, and that's the best you can manage, it doesn't make you feel desirable.

As well as dealing with a whole host of other issues, and hormonal changes, your desire for someone you really love tends to fall off a cliff. Couple that with wondering how they may still want you with greasy hair, untamed eyebrows, and hairy legs... well, it's hard to be a 'femme fatale' when you can't even cut your own toenails!

During lockdown, lots of healthy women have talked to me about not being able to access hair and beauty appointments, putting on weight, being bored, and lolling about in loungewear. It's actually been a great leveller.

I think for any partner it's a challenge and caring means feeling taken for granted, too. Any needs that arise are quashed. It's a bit hard to approach someone for sex when you've just rescued them from the bathroom floor... again!

Humour and communication are key. I find sex to be painful, and the idea of the 'whole shebang' is too much for me. Avoiding it altogether has damaged my marriage. Physical intimacy of any sort counts. Sometimes my husband just wants me to place my hand on his shoulder when we wake up. In these difficult times, we are lucky we can share that.

Sex is never really like what you see in films or on TV, is it? He's never going to sweep me off my feet like Richard Gere.

If he has to carry me, it is another kind of rescue. I'm hardly Uma Thurman in that famous rubber catsuit. I mean wearing a waterproof bib isn't exactly the same, is it?!

Your article reminded me that I'm not alone with these thoughts and struggles. And that talking and listening matter most.

I may even pluck me eyebrows in celebration! My husband will think I'm getting ready for a red carpet....

“It’s a bit hard to approach someone for sex when you’ve just rescued them from the bathroom floor... again!”

- Joanna



“My partner is incredibly understanding about my condition and very supportive. As always, good communication is the key”

- Henry



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VICTORIA'S STORY

I am lucky to have good function with ME/CFS provided I manage my high energy tasks evenly through the week. This is why my partner and I reserve Sundays for intimacy, Sunday, Funday.

We always go by how I'm feeling. 98% of the time it's mutual masturbation and or oral sex as a side-by-side position requires less energy.

Sometimes I will indulge even though I am fatigued as intimacy is important to me. On these occasions I struggle to orgasm and when I do, I crash for a few days. On the days I feel I'm too fatigued we snuggle instead.

"I'm very impressed that the ME Association has had the strength to print an article about intimacy. My wife has had ME/CFS for a long time and sex is no longer on the agenda. It was good to have a man's point of view too, especially as Fiona and Matt seem to be in a similar position to us.

It has been very difficult to come to terms with my wife's condition and all the problems that go with it. She can't work anymore, she can't face going out, doesn't think she can ever go on holiday again and spends most of her life on the sofa now.

It's a far cry from what our life used to be and can be quite depressing. We haven't talked about sex for years but the article opened the conversation again. I even bought her 'something lacy', she put it on and it made her smile!"

- Martin



ME CONNECT
The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid

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