



Association des Aidants et Malades à Corps de Lewy
www.a2mcl.org

An open letter to our friends and family

*Co-written by people living with the same
invisible and disabling disease*

Dear readers,

Will you spare a moment of your time to read me?

Understanding us is the first step towards helping us. Living with the Lewy Body Dementia, we have thus written this letter for you, whether you are a relative, a friend, an acquaintance, or a colleague to enable you to further understand us.

It's difficult for us to find the right time or the right words to express our feelings, which is why we chose to hand you this open letter you can read whenever you choose to and as many times as you like.

I am suffering from Lewy body dementia.

The goal of this letter isn't to describe the illness but rather to describe what it's like to live with it. Although this disease affects people differently, and comes with diverse symptoms, you need to know that being self-conscious sometimes leads me to hide some symptoms. You can imagine that I might be ashamed to have this neurodegenerative illness that I might feel stigmatised because of all the negative connotations associated with it. I often feel discredited and sometimes excluded, even rejected.

First of all, this illness tires me or more precisely: it exhausts me. It can lead to a global attention deficit. However, don't be misled, this doesn't mean I am not interested in you or in others, it's just I can't process too much information at once.

This illness also leads me to become disorganized on a day-to-day basis, partly because of my many sleepless nights. Some days you might see me in a "good shape", going as far as to be hyperactive from time to time, while on others, it might not only lead me to walk and speak slower, but also to temporarily lose memory, fall down, shiver, and to have visual and auditory hallucinations my illness is characterized by its daily fluctuations.

The many difficulties accompanying this terminal illness also increase my anxiety towards the present and the future, a lack of confidence in myself, and my irritation: I develop an acute hypersensitivity with every surrounding behaviour.

All these differences are also part of my illness, but most importantly are part of me on a daily basis. It's not laziness, nor simulation, it's just who I am. I might not look like it, but I'm seriously ill. Lewy Body Dementia isn't an illness you live with, it's one you die of.

Let's cut to the chase, I need your help:

In any kind of way you can and you wish to give it to me: however you decide to help is up to you. I need it although I might not be asking for it directly. If I am not asking you for it is because it's difficult to admit that I've changed, that I'm not the same person. This change is source to some form of guilt on my side, since, damaged by this illness, I can't give you the same quality of relationship that I used to.

From then on, I'd like to state my demands:

It goes without saying that I would like you to read and reread this letter so you'll have a better understanding of my invisible handicap. Then, I would like to be helped on a day-to-day basis; my needs will vary depending on the stage of my illness: you can find someone to do what I used to do, to help me in completing the tasks I can still do but with difficulty or that exhaust. However, this help demands constant patience and a lot of warmth and an understanding of how difficult it might be to perform even the easiest daily tasks. However, I do not want your pity.

To be truthful, I would like you to understand my need and to accept their evolution.

I would like to receive your tolerance and your patience concerning my progressive increasing limitations. Your help is essential: each help, each word enables me to not surrender to the anxiety that the illness is giving me. They help me to resist a little longer and fight against this condition.

I would like us to stick together. Sometimes, I feel cast out by my friends and family because of this illness and even though I may be leaving you a little bit, the warmth of our relationship does not leave me. I would also like you to help me communicate to others about my illness. It's difficult for me to share what it feels like to live with this invisible but deadly pathology, without scaring or leading people away.

In one word, to help me fight against this illness, I would like us to search together for the last rainbow before I become the ghost of what I used to be.

THANK YOU for your understanding

16, rue Marx Dormoy 75018 Paris • 06 62 63 34 97 • contact@a2mcl.org
www.a2mcl.org    #a2mcl