

Thoughts from the Exeter Lived Experience Group

#### For further information on depression and services available locally, please contact:

www.devonpartnership.nhs.uk

www.recoverydevon.co.uk

www.rethink.org

www.exeter.ac.uk/leg

Grateful thanks to the family whose generous contribution paid for the printing of this booklet.

#### **Credits**

Thanks to John Hales, Rosalind O'Dell, Dan Bullock, J Harding, Toby Pearson and to South Devon Area of Outstanding Natural Beauty for use of photographs. Also to Teddy for his picture.

Thanks to all who shared their experiences of depression and their tips for keeping well. Special thanks to Alan, whose hard work in putting together the various scribbles, notes and ideas made a publication which the Lived Experience Group are proud of.

Cover photo: John Hales

#### **About this Book**

This publication was generated by members and friends of the Lived Experience Group (LEG) of the Mood Disorders Centre (MDC) of the University of Exeter.

The purpose of the 'LEG' is to actively encourage a co-operative working relationship between members of staff of the MDC and people with lived experience of depression, bipolar disorder and supporters of people with these conditions. Examples of areas in which people with lived experience may work with staff are as follows:

- Consultation on materials used in clinical studies, such as participant information sheets
- Membership of steering groups for research studies, advising on the direction studies should take
- Membership of groups tasked with reviewing protocols, curricula and policies
- Involvement in training, including undergraduate students, trainee clinicians and therapists
- Running workshops in the community aimed at disseminating knowledge of mental ill-health and reducing stigma.
- Assisting in the selection of staff and students
- Generation of research ideas

These are just examples and as the LEG grows, so, too, will the number of different types of activity in which we become involved. We hope that you will enjoy reading this publication, which gives an insight into the lives of people living with depression, as well as some practical tips on keeping the 'Black Dog' (as Winston Churchill used to call his depression) at bay.

For further information about the Lived Experience Group, please email: legexeter@live.co.uk

### The Strangeness of Raisins

In one of the mindfulness exercises on the Exeter course people are handed a raisin and asked to study it as though they've never seen one before...

It's intended to help focus on the moment to appreciate the now... When he gave her a raisin, the woman wept.

When he asked her to consider it as a child might, or a Martian, she studied his face then she looked at the inscrutable ingot of sundried grape wondering if her doctor had sent her to the right place. For how could a raisin cure the lethargy that leaked from insomniac nights into feeling-bleached days?

But the teacher was gentle, he asked her simply to look, to wait and watch with an openness of a child. To inquire of raisin wrinkles:

are you the laughter lines crinkled round the eyes of an old buddha? Are you fig or almond flower?

He said, listen to your raisin like you might if you thought it were the heart of an unborn daughter. But the woman stood, still quietly weeping, eyeing us with fear as if we knew the dark secret of raisins.

When she left the room, I felt a slug pellet of guilt for a moment before it bloomed into a simpler mood, a sadness grown muscatel soft. And I sat, just breathing it in, til that feeling titled and rose like wren, lilting then changing its tune. And I felt something like love. Love edged with the fragrance of raisins.

So my wish for me and for you when we are next hanging from a thin raisin rope or sinking beneath a sea of dark puckered fruit is that we can summon something like the simple sweet of a raisin for our own estranged selves.

# "Life isn't about waiting for the storm to pass ... it's about learning to dance in the rain."

I have suffered from ill health and depression for years now and put my whole life on hold telling myself that I would do this, that or the other when I felt better, only I never did get better.

I didn't realise that getting out there and getting on with things was part of the recovery process. Of course, I still have my off days but when I catch myself putting things off because of my pain or depression I remember the quotation and push myself to get up and "dance in the rain".

Laura S

#### Compassion

In the field of mental health, compassion is a very important feeling. Primarily, we know that therapists feel a lot of compassion for their patients, who in turn are helped by this.

However, another way of using the therapeutic value of compassion, is for the therapist to attempt to instil this feeling in their patients, so that the patient starts feeling compassion for himself or herself.

I am sure you will agree that this is not easy. Generally, people are not very good at this, and it is more often the case that one tends to mistreat oneself. When you are unwell with depression, it seems even more impossible to feel positively towards yourself. Yet, it is worth going against the negative grain and cultivating an attitude of self-compassion; it is good for us! I said 'attitude' rather than feeling, because maybe at first, this is all we can hope for: a rational disposition, an intent, rather than an overwhelming, warm surge of compassion!!

A couple of tips to help? First, what I have found helpful, is to remember the kindness of all the caring people

I have come across, be they professional people, friends, neighbours, your children, members of your therapy group...etc. So I remember the compassion of others and I think to myself that the least I can do is to try and prolong those feelings myself by keeping some self-compassion going. Remember a word, a look, a hand, an embrace...and how comforting it felt to be receiving it, or





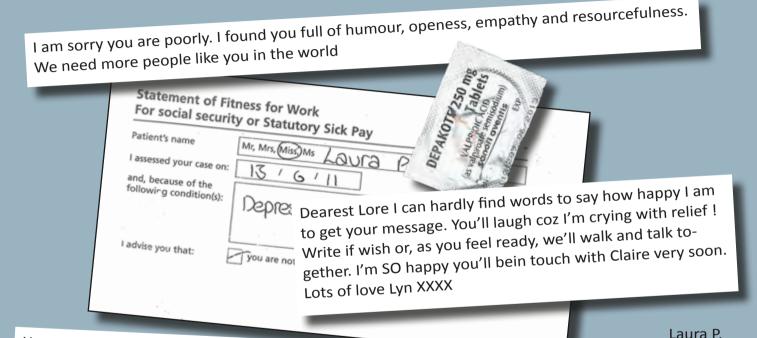
indeed to be giving it, if you felt drawn to somebody who was suffering, with feelings of compassion.

There is also a powerful analogy or image, which really works for me, that of a mother or father comforting a child who is hurt... (I have tried to draw them both, in a very simple way, forgive me!). Of course, one can think too of a husband comforting his wife and vice versa, or any grown up comforting one another, but I think you will agree that there is something unique, very strong and universal about the relationship between a parent and his child, something that even people without children of their own can feel. I think that it is because of the inherent fragility of the child that this never fails to move us.

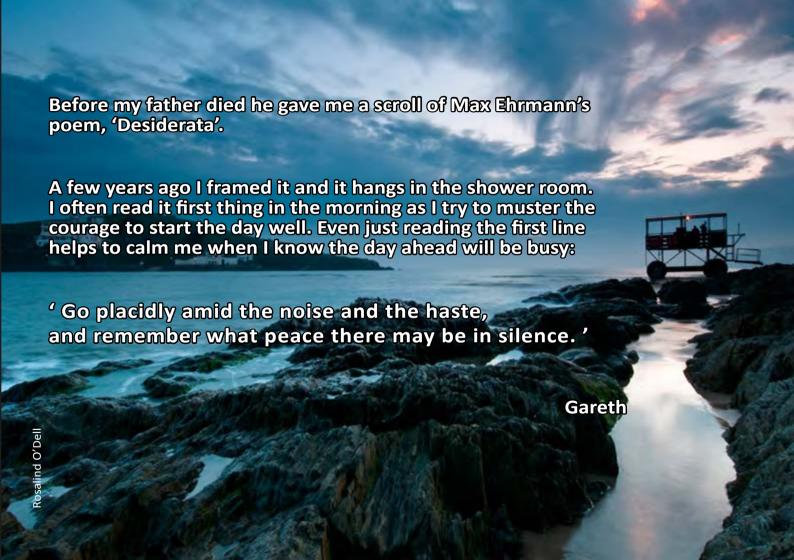
I find that I can relate to this idea or image, I think of the very many times I have comforted my children in pain, how the comfort I have given has soothed the pain and what a miraculous cure this compassion is! So I ask myself if maybe I could start feeling a little self-compassion towards myself: what about treating myself gently for a change? When I am depressed, I know how diminished, how vulnerable and weak I feel...I am like a

child then...I need all the self-compassion I can muster. When I have difficult thoughts and feelings, instead of getting angry with myself, or letting anxiety take over, I can accept and embrace them with compassion, like the mother and her child. Indeed I can be both the mother and the child.

# The passage of time and the warmth of friendship helped me



Hey Laur really good to hear from you! Have been worried about you obviously but wanted to give you space and knew you have the strength and wisdom to come through. The world has felt empty without you, sorry its been so hard Lots of love Claire XXXXXXXX



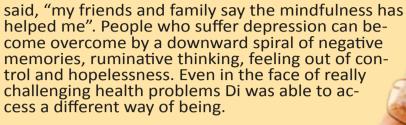
#### Breathe.....

I first met Dixon Cowan ("Di") in March 2006 when he enrolled in our mindfulness therapy research trial to establish if it could be helpful to people like Di, as an alternative to staying on anti-depressant medication long-term. When Di explained what he wanted to get out of the mindfulness course he said something quite unique: "I want ways to deal with my health problems better, so that I and the people around me are better off."

His earnest wish to change so that both he and his family and friends would be happier was something I saw evidence of throughout the 8-week mindfulness course. Mindfulness courses involve learning how to use a range of mindfulness practices to become more aware of thoughts, feelings and bodily sensations and relate to them with curiosity, kindliness and equanimity. Sometimes we use readings to illustrate how mindfulness can help step out of old patterns of reactivity that can trigger depression.

During one of the sessions Di explained to the group that he was a fan of the singer song-writer David Gray, and that many David Gray songs were resonant with what he was learning in the course. At the end of the programme Di said mindfulness has "given me the ability to come up against something that would have previously thrown me, think it through, come up with a solution and then move on. It has given me a road to travel; I am not alone with regard to my difficulties, I am not isolated." At the end of the programme I bought some David Gray CDs and saw what Di had meant.

Shortly after completing the trial, Di was diagnosed with 'multiple myeloma' and had to undergo treatment, including a major spinal operation, which left him less mobile than he was before. He managed his illness and pain in part using the techniques he learned in the MBCT course. More than once I had emails from Di on hospital wards where he was receiving treatment. He didn't say, but I knew he was probably experiencing a lot of pain and discomfort. Yet his emails were light-hearted and filled with humour. As with the first time I met him, his emails always had an appreciation and concern for others. In one email he



As David Gray says in his song Breathe:

"Your crenulated wealth, Your educated self, Your family, Your rude health, and all the joy it brings. Aren't we forgetting something, feet out on the ledge and Breathe, Breathe, Breathe."

Sadly Di passed away earlier this year. Every time I hear a David Gray song I feel a sense of gratitude that our paths crossed, that my work was helpful to him and that my life has been enriched by knowing Di.

Willem Kuyken,
Professor of Clinical Psychology
& Co-Founder
Mood Disorders Centre,
College of Life &
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University of Exeter

# Learning to live with depression

"I have experienced recurrent depression over the last 10 years and would

say that although it has been a traumatic experience in many ways I believe that I have become a better person as a result. I feel that personal suffering makes you more insightful and compassionate for the human experience.

I have found the following things have helped me through my depression :

- Giving myself time to recover
- Support of family and friends
- Exercise, fresh air and a good diet
- Maintaining medication; I have relapsed when I have come off it
- Plenty of fresh sunlight at home; using a light visor in the winter to avoid SAD
- Wearing lots of bright colours
- Realising that I am not a weak but strong person to have got through my episodes of depression, and
- that at the end of the day I am a 'good enough' person..... "

# Of Love and Lard

As for my friend who calls to say,
"I'm as useless as a lump of lard,
useless as a cemented spaghetti strainer,
useless as a spittoon to a spinster."
I interrupt, since she has lived through
several wars, and has kept the noose
from the neck of several friends of ours.
I ask her since when did a block of lard
ever suffer the hair-shirt of life, of loss?
And who ever said useful was the defining
attribute or best gesture of the beloved?

Dana

# My Mood Lifebelt... 'Me n Oscar T'

I use my Mood Lifebelt when it feels like I'm drowning. Doing something from the list (even if my mood stops me enjoying it at the time) can help me get back to the shore...

... and to 'T'! - Thanking my friend for asking "Is it time for Me 'n Oscar T?".

M	Meditate	Do a mindfulness exercise
E	Exercise	Walk the dog or a cycle ride
'n'	Nature	In the country or by the sea
0	Organise	Tidy garden, clean the bike
S	Simplify	Throw out junk
C	Create	Make espresso, pot up a plant
A	Appreciate	Favourite music, birdsong, etc
R	Relationships	See or phone a friend
T	Thanks	Pat myself on the back & thank others

Cliff

#### Life with a backpack

For me, living with depression is like walking through life carrying a huge backpack – an extra burden to carry as I go about my daily life. I have carried a backpack for as long as I can remember, certainly since childhood. It has represented different mental illnesses at different times; anxiety, OCD, anorexia nervosa, depression, often more than one at a time!

Sometimes the backpack has been so heavy and burdensome I have scarcely been able to lift it and life has become unbearably difficult. Other times it has felt lighter and I've almost forgotten it was there. I've even put it down and left it somewhere a couple of times but as it's clearly labelled with my name and address it always seems to find its way back to me!

Despite many years of various therapies and antidepressants I still have a backpack. So for me, "recovery" has meant finally accepting that this backpack is a part of me and I just have to find ways to deal with it. So, here are some of the things I have found most helpful and I share them with you in the hope that you find them helpful too.

Family. For many years I kept the backpack a secret. I shouldered the burden alone and just battled on, raising a family, keeping the household going, managing the menagerie, holding down a demanding job. Finally the backpack became so heavy I just crumpled under the weight. I realised I couldn't keep going on alone. Couple's therapy was the turning point for me. Together my husband and I, supported by an excellent therapist, unpacked the backpack, had a jolly good look at what was in there and then packed it all up again. Guess what, it was much lighter once the burden had been shared. I also keep a large photo of my two beautiful girls firmly attached to the backpack. When times are bad and my thoughts are dark that photo is an instant reminder that I always have something to live for.

Friends. Time off work has allowed me time to develop friendships. I have found true friends who love me unconditionally, whether I am happy, sad, grumpy or angry. Friends act like bridges, they reach out to me and drag me out of myself, to a dance class, for a run or just to give me a hug. It works both ways too. Many of my friends have backpacks of their own, and sharing the contents of these with each other again lightens the burden. I represent my friends by the mobile phone in the photo. Even if I don't feel well enough to phone, a quick text will connect me to someone who cares.

**Hobbies**. My hobbies play a huge part in helping me cope with the backpack. Playing the guitar is my meditation — a great way to turn off that tape that fills my mind with negative thoughts and ruminations. I run, I dance, I walk the dog, I take care of our dartmoor pony. All of these activities bring me into contact with people and it is that human contact that makes the backpack so much easier to carry.

Finally, **memories**. Depression is a very isolating illness. If I am not careful, long periods of time pass with few new happy memories to reflect on. It becomes too hard to drag that backpack to a party, or a wedding, or a night out with friends. I now recognise that I need to make the effort, ask for help with arrangements or with transport because that special event or day out or holiday will make a difference; a shared experience to talk about, laugh about, cry about.

So, I still have a backpack. I think I may always have a backpack. If I just keep fighting it and pretending it's not there eventually I believe it would crush me. My "recovery" has been about facing facts and accepting that I have to make big changes to my lifestyle to accommodate it. It is a "work in progress" and it is jolly hard work! But I know it will benefit both me and my family in the long run. I can now accept the backpack as a part of me but I refuse to let it define me or destroy me.

### Compassion

What a tree can teach you...

About halfway through the Mindfulness Course, whilst walking in the field with my dog, trying not to "ruminate" and think about the past or the future, but concentrate instead on the present moment, I had a very striking experience. I was making a deliberate effort to be open to the outside world and be aware of sensations in and around me.

The tall winter trees looked bare but beautiful in the crisp morning light and I found myself drawn to one in particular. I kept my eyes on it, as I was approaching it and all the visual sensations of this tree felt suddenly very vivid and different. I also felt very comforted, very peaceful. I was struck by the fact that I felt a kinship with the tree: it was there, calm, erect, dignified, grounded, mindful of itself only, simply intent on being



a tree, existing fully every second of the day, "moment by moment, with seamless continuity", to quote Jon Kabat-Zinn's familiar phrase...What a wonderful model this tree is for me...if only I could become a tree!!!

I hope that this doesn't sound too odd to you, dear readers, and that you can relate to it, somehow.

I think I did become a tree for a few seconds on that memorable day... but what I want to say to you, is that this kind of new and fresh experience is one of the precious things that a mindful attitude can bring you.

If you turn your back on depression, you have to reconnect with other things: a richer, more direct experience of the world, a richer, bigger self as a result, are worth aiming for! We can all do it!

I have a card stuck on my fridge, which has an anonymous quote:

"Everything will be ok in the end."

If it's not ok, it's not the end."

I repeat it to myself when the going gets tough.

Kendra

"Be a lamp until yourself and seek your own liberation with diligence"

Buddha - Last words

I have a very, very dear friend, who has a bit of a mantra that I use:

"The sun will always come up in the morning"

Kendra

# **Everything happens for a reason .....**

Once, when I had been very ill and was leaving hospital after a 2-month stay, my named nurse told me that she believed that everything happened for a reason. At that time, I found it hard to believe or understand. But several years on, I think she was right.

On the very first, awful day that I was admitted to a psychiatric ward a young woman who had been a patient there for a couple of weeks, found me sitting alone, miserable and very, very frightened. She chatted to me and offered to show me round, which helped me so much. She was going through a hard time herself, despite having a new and very supportive husband. Well, things moved on, she was discharged and eventually so was I. Despite our age difference (I'm old enough



'Being on the beach with my family makes me happy' by Teddy, aged 5.

to be her mum), we became great friends — a friendship that has endured even though we now live a long distance from each other. She phones me every week and knows immediately if I'm 'wobbly', as I do with her. I don't have any family of my own and my friend's parents really don't want to know. But I have three 'honorary grandchildren' now. My friend bestowed this title on me when she had her first child, because she wanted her children to have a grandmother who they could be naughty with! I get lovely cards and drawings which the two oldest

and drawings which the two oldest make for me, which always make me smile.

Unless I'd been through that dreadful experience of being taken into a psychiatric ward, I wouldn't have met this delightful young woman, or become an honorary gran.

So, maybe, everything does happen for a reason.

#### "Thanks, Coco"

Cat on lap, hand on warm fur
Both of us quietly content
Unrelenting anxieties and dark,
dread-filled days forgotten,
sun-warmed skin replaces a cascading
carnage of thoughts
... but for how long?
I catch myself and simply enjoy the moment.

I catch myself and simply enjoy the moment Tears wet her fur as I whisper

"Thanks, Coco"

Cliff

# Things that brighten my day

My grandsons – Thomas and Barnaby
Parachutes wafting across a clear, blue sky
My husband's unconditional love
Sitting on a sunny beach
A vast panorama of sky and sea
A golden sunset
A rainbow
A smile

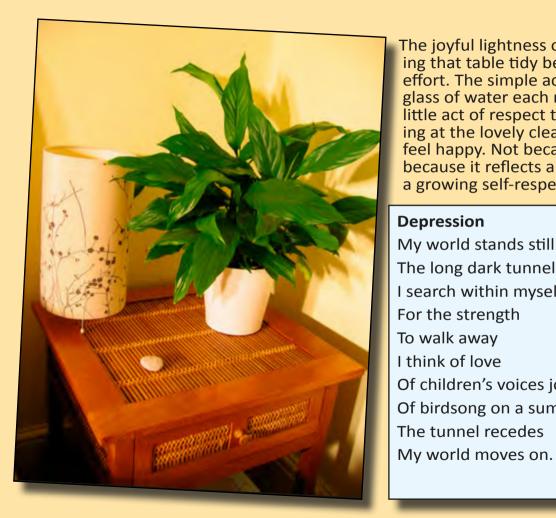
Elizabeth

#### Recovery

I really don't like that word. It is loaded with expectation and meaning. Recovery implies that all is well, the hard work is done, and life is back to normal. I find I have to work really hard at 'staying well'. For me the difference between 'recovery' and depression is that the work of being well is much easier, that I'm happy to do it.

My bedside table is a good barometer of my journey through depression to wellbeing. An outsider might look at that image of the messy table and think 'lazy'. It's not that I wouldn't agree with you. After all, when I'm down nobody could insult me worse than myself. But there is so much more going on with that table. The depressed me is just too sad and tired to tidy up the mess. Most damagingly, I just don't feel, deep down, that I deserve anything good, clean or nice. At the same time as feeling sad, tired and worthless, another part of me is berating the poor inner me for being such a disgustingly lazy slob.





The joyful lightness of feeling well is keeping that table tidy because I'm worth the effort. The simple act of tidying away the glass of water each morning is actually a little act of respect towards myself. Looking at the lovely clean table makes me feel happy. Not because it looks nice but because it reflects a kindness, a softness, a growing self-respect. This is recovery.

#### **Depression**

The long dark tunnel beckons I search within myself For the strength To walk away I think of love Of children's voices joyous in their play Of birdsong on a summer's day The tunnel recedes My world moves on.

Elizabeth

# Black dog symptoms

Black dog symptoms Are hard to tell apart From those of new love.

Frenzied bursts of action, Thoughts bowling in a groove, The loss of concentration.

Mind stalled and stationary Encased in concrete, Graffitied breeze-block walls.

New love runs a converse course Symptoms and outcome identical In all but hypothesis.

The rollercoaster of passion, Sleepless nights and hidden Omens cupped by superstition.

Loss of appetite and reason, Careless thoughts as the mind Curves to an alien will.

Like love the black dog ages, Pigment softens, turns grey With everyday banality.

# Little white dog helps in fight against black dog

I met Kadie in 2008. Her owners had divorced, neither could take her and she was temporarily living with a friend of mine. But she needed a new home, so she came to share mine.

Words cannot describe what a difference this little creature (she's a Westie) has made to my life. As most people with depression will tell you, one of the most challenging acts some days is actually getting out of bed; the next challenge is to get out of the front door!

But who can resist that happy little face, so looking forward to her early morning walk. When I think of the number of times in the past when I've thought I should get out into the fresh air, only to decide that it was too much bother and walking for no reason just seemed pointless. Now, come rain, hail or (occasionally!) sunshine, we're off along the seafront. My head, sometimes clogged with thoughts I'd rather not have, gets a chance to unwind a bit; my aching joints ache less for having some exercise; and the joyful way that Kadie plays and runs and sniffs and wags her little tail at anyone who has a kind word for her helps to fight that black dog that lurks around the corner.

Kadie seems to know when the black dog is around and she'll bring me one of her favourite toys to play with. She gives me that thing which we all seek – unconditional love. That big black dog still comes round from time to time, but my little white friend helps me fight him off.

Steph

### The gift

Some years ago I met an elderly lady who had lived in various institutions for

people with mental ill-health since she was a young woman. I suspect that she might have been 'naughty' in her youth and, as happened all too often in those days, she was sent off to an asylum. She was to spend the rest of her days in such places, although now, of course, they are not called that.

One day, she asked me if I would like to see her 'treasures'. This turned out to be an old biscuit tin. Inside were some photographs. One was of her brother at his graduation. She was so proud of him! Her treasures box also contained some notebooks, one with poetry written in her own hand and she pointed out a couple that she particularly liked. I asked her if she had written them and she smiled and said she had. Whether she had actually made up the poems or simply copied them wasn't altogether clear! But it didn't matter. They were special. That biscuit box, with its photos, notebooks

and a few little trinkets was all that that woman owned in the world, apart from a few clothes, bought from charity shops. But she gave me two very precious gifts. She knew that I loved reading, but she didn't have much money to

PRIDE AND

PREJUDICE

JAME AUSTEN

buy something for me. But she found out that a Sunday newspaper was giving away free copies of 'Pride and Prejudice' and that was her gift to me. That book means more to me than any first edition could, because it was given with such generosity of spirit.

And her second gift? She gave me hope. I had been feeling very down one day and said to her that sometimes I just felt like giving up. She looked at me with a determined gleam in her eye. 'Never, ever give up', she said. For all the hard knocks and difficult times that this woman had endured, she had never given up hope. That, too, was her gift to me and one which I have to this day. When things are looking bleak, I think of her and the hard life she must have had. If she could endure that and still have hope, then surely I can, too.

Let yourself visualize the effects of unskilled thought patterns such as annoyance, anger, selfjudgment, and so forth. Inwardly see how such thoughts affect you: the tension, the raising of your pulse rate, the discomfort. Outwardly see how such thoughts affect others who hold them, making them upset, rigid, even ugly. Then make the compassionate determination, 'I will never allow such states to make me lose my peace of mind'.

The Dalai Lama

On those days when I can feel the dreaded fuzz of depression daring to rear its ugly head under the pressure of deadlines, trips to the dentist, shopping, and all the other stresses of daily life, I try to remember the soothing words of my countrymen and women......

"Feck it. Sure it's grand."

Julie

#### What I've Learned

I've learned about depression through my wife having to live with it.

For many years, as with most people, I just didn't get it and I felt resentful of having the person I married stolen away and the things that we used to do together being replaced by cancelled events and solitary activities.

I think I learned how to make things worse. It has taken much longer to start to learn how to make things a little better, to support and to understand and not feel angry and resentful.

I think it would have helped to be more included in treatment processes. It often does take some effort to understand what's happening, take a positive line, and I still have times where the understanding and patience seem too much. In the end though I think the disease which could have split us up has helped us to work out a better relationship.

In the 12 years or so we've lived with this, my refuge has been music and occasionally I write a song – usually only when there's something I really want to say. I think those that have suffered from depression may resent the simplistic implications; I realise depression isn't a 'lifestyle choice' – but even with support, it seems to me that learning to live with depression has to come from within.

If you want to hear what 'Into Every Life' might sound like (as I'm not sure it makes it as poetry on its own!) then you can at: tinyurl.com/77k68bh

### **Into Every Life**

Into every life, a little rain has got to fall Let me tell you sister, that you've really had it all Some days you never made it out of your bed Some days you never made it outside of your head

What doesn't kill us makes us stronger so they say You should be getting stronger nearly every other day You need to understand that a day with the rain Doesn't mean the sun won't shine again

You start each day on high,
With the wind beneath your wings
You fly too near the sun,
Then your feather's gonna singe
A misplaced word, you spiral down
You've got to climb back up – reclaim your crown

Into every life, a little rain has got to fall Let me tell you sister, you need to have a ball Carpe diem, go seize that day Decide that you want to go another way

#### **Freedom**

I ran along the shore with arms outstretched and head thrown back
An attitude of gay abandon captured me and led me on
The wind sang sweetly in my ears, the salty air flung fondly to my lips,
I raced into the surf to meet its challenge with a laugh.
The pounding of the ocean left me breathless, still,
I sprang up once again and ran towards the sun
That now had risen from the hills to greet this day and say,
How wonderful it is to be alive.

Anne S. Lived Experience Group Member