Crippling pain for company

Where is the kindness and support in S’pore, asks chronically-ill lass

JOANNE HO
22, business student

At 22 years old, Joanne Ho lives with the kind of crippling, unrelenting pain you’d more often find in a sickly person three times her age.

She has been diagnosed with four chronic illnesses since she was 13, though you’d hardly think it was true because of her sunny disposition.

“T’m sure God has a bigger plan and what must happen will happen,” she says, punctuating every other sentence during the interview with a laugh.

Four years ago, a routine appendectomy operation led to adhesion colic, a condition where her internal scars failed to heal and now cause her intestines to entangle.

A frightening idea, but... “It’s just like bad cramps,” says Joanne, adding cheekily: “And that is just the start.”

She has since also been diagnosed with inappropriate sinus tachycardia, neurally medicated hypertension (NMH) and fibromyalgia.

Joanne, the daughter of a bank employee and homemaker, laughs all this off: “I am just a young person with old person pains lah.”

Her ailments, though not terminal, leave her crippled with pain through the day, inducing fatigue and fainting spells.

“The pain comes and goes, lasting from six minutes to six hours and at times up to five times a day,” she says matter-of-factly.

Instead of wallowing in self pity, Joanne is gunning to start a support group for chronically-ill people here.

Pointing out the colourful cards pinned on her bedroom wall and packages piled by the bed, she muses: “It helps to know there are people out there who understand what you are going through and who care.”

It has been an opportunity to appreciate the importance of kind strangers — and, sadly, to be aware of how few of them there are in Singapore.

“I remember the first time I suffered an attack of NMH, I was on the MRT on my way home,” Joanne recalls. Doubled over in pain in the crowded train, she thought she was going to die.

“There was a sudden sharp pain and my heart started to race.”

Yet, nobody stepped forward to help her, leaving her to alight at the next station and seek help on her own.

“Singapore claims to be an advanced society but when it comes to basic kindness, we are sorely lacking,” she says.

Her frustration is more apparent when she discusses the lack of support networks even in hospitals.

“It’s not just about emotional support, but even in terms of pain management and doctor-to-doctor communication, we are really inadequate.”

She shares an incident when two different doctors treating two different illnesses prescribed medication that could have been a potentially-fatal combination.

She explains with relief how her United States-based Internet support group caught on when she casually shared her latest prescritions.

Fortunately, my friends realised it immediately and told me to make sure, and they were right.

These online friends have come to be very important to Joanne, even encouraging her to keep a blog to chronicle her daily battles and thoughts.

It is this sense of understanding and camaraderie she has been unable to find locally.

“Can you believe it that I have yet to find a single person my age with similar illnesses in Singapore? And I doubt it’s because I’m the only one.”

Her online community helped her find an “adopted” family in the US, with whom she intends to live when she goes there to study later this year.

“I know, I shouldn’t be so critical of Singaporeans but it is just that everything amazing has come from American strangers.”

Looking around her room again, she declares that almost all her gifts came from her online friends. Picking up a quilt, she wonders aloud about how remarkable it is that strangers would go to so much trouble to bring cheer to a girl they barely know.

“I’ve tried sewing a quilt before, it is not easy... These people are really wonderful and I can’t begin to explain how much we need such support groups here.”

Especially so, since Joanne realised her ailments were compromising her ability to perform at the Singapore Management University where she is a third-year student.

“The medication and the pain just cloud my mind, and I need 10 minutes where others take five to do something,” she says.

Hoping to be given some leeway, she has printed scientific findings off the Internet to show to her lecturer, but “as one individual, it is very difficult to make such requests”.

Joanne confesses to having “no idea where to start” in setting up that support group — but she knows it must be done.

“It is essential to know you are not the only one, and we can all pool resources and cope and learn together,” she says.

As told to Surekha Yudav