



Rosa

Rosalind Amor has been an enthusiastic supporter of the Let's do it for ME campaign since its launch just over a year ago, as one of the first members of the online planning group and also of the Make ME Crafts team, as in spite of severe illness, Rosa crochets soft wool blue awareness wristbands when able to for Invest in ME.

We wrote about Rosa's Wristbands in March and she raised over £100 for ME Awareness Month in May but by July her hands had become too weak to crochet. Following a decline in health, Rosa spent most of August and September in hospital and she is now in a Nursing Home being fed by a naso-jejenum tube.

Rosa will be 21 on 9th November and, in her usual inimitable fashion, she has a very clear idea as to how she wants to mark this significant birthday. She plans to use her 21st as an appeal for the Let's Do It For ME (LDIFME) campaign to raise funds for biomedical ME research at a centre of excellence in Norwich.

Rather than sending her cards and presents, Rosa is asking her family and friends if they can raise awareness and money for this cause which is so dear to her heart. As she said in July, "I so wish we could get this centre running, I need it!"

For the occasion, Rosa's mother Julia prepared party bags containing a blue balloon, a LDIFME badge, ME awareness poster, leaflets and a card in which Rosa tells her story ...

## Rosa's 21st Birthday – 9th November 2012

All I want is to be like other 20 year olds; to travel and go to uni; to socialise and be independent; to walk, swim, dance and ride. I've already lost a decade of my life to this wretched illness. Please don't let me lose another.

I've had ME for 12 years. Before that, I was a healthy child. I was always playing; I loved Puppy and Kitty in my pocket sets; I went to ballet and modern dance lessons, swimming, watch club, was learning the violin and was a junior member of the RSPCA.

When I was eight my grandma and hamster died in quick succession, followed by a unknown virus of the gut. I had a terribly high temperature and was sick on everything, even water. Unfortunately, I didn't recover. I was diagnosed with ME quite quickly but sadly, this didn't make my treatment any better. I was admitted to hospital and given physio, then sent home and relapsed terribly.

I don't remember the following year. I know I lived on Complan all that time until we finally persuaded our doctors to give me a tube. I was admitted to hospital again for a few months – a painful experience.

I was paralysed and bed-ridden for 7 years and was tube-fed for 5 and a half. I remained at home, cared for by my parents. My symptoms included; paralysis especially my legs and swallow, hypersensitivity, headaches, muscle pain, 'brain fog', muteness, orthostatic intolerance, insomnia, spasms, severe nausea with a period of vomiting and extreme tiredness.

At 15 my health dramatically improved. I was able to stand and use a wheelchair. Briefly, I was even able to walk independently around the house though still needed a wheelchair outside. I became involved with my local wildlife trusts, visiting their reserves, attending 'wild learning' courses and part of a youth group.

However, from the end of 2009 my health slowly worsened again until last year, when I had a tooth infection and a bad back, I had a major crash. My worst problem this year is vomiting which worsened my tiredness, hypersensitivity, cognitive functioning and insomnia.

I always believed that one day my body would naturally heal itself and I'd return to my previous levels of health. Now I'm less confident of recovering unless someone finds a treatment.



How you can help to celebrate Rosa's 21st:

- Put up an [awareness poster](#) where lots of people will see it
- Wear the Let's do it for ME [badge](#)

How to donate:

- Online to Rosa's Justgiving Page by visiting [www.justgiving.com/Rosa21](http://www.justgiving.com/Rosa21)
- Send a cheque payable to Invest in ME to:

Invest in ME,  
PO Box 561  
Eastleigh  
Hampshire  
SO50 0GQ

Please write 'Rosa's Appeal' on the back

- Make a direct payment to Invest in ME –  
Bank: Lloyds TSB Eastleigh  
Sort code 30-92-94

Account number: 02252685

Please mark your donation 'Rosa's Appeal'

To find out more about the Let's do it for ME campaign and other ways to help visit [ldifme.org](http://ldifme.org)

To find out more about Invest in ME visit [www.investinme.org](http://www.investinme.org)

To read about Rosa's Wristbands <http://blog.ldifme.org/2012/03/rosas-wristbands.html>

You can read more of Rosa's experiences in her own words on her blog <http://rosalindamorspaceofameguineapig.blogspot.co.uk>