



our mission is to care, our vision is to cure

Star Supporters:

Identifying and meeting the needs of carers of haematology patients

20 March 2015

A support group to meet the needs of carers

- Leukaemia & Blood Cancer New Zealand
- Identifying the unmet needs of carers
- Overview of relevant literature pertaining to carers' needs
- Experience of setting up a support group specifically for carers of people living with or beyond a haematological malignancy.

Leukaemia & Blood Cancer New Zealand

- National organisation dedicated to supporting people affected by a haematological diagnosis
- Individualised psychosocial support enabling patients and family members to adapt to, and cope with their diagnosis
- At any point from diagnosis through to survivorship
- Recognised many unmet needs of those caring for haematology patients
- No current intervention specifically for this group

What is a carer?

- 430,000 people in NZ (Census, 2013)
- Provides more than four hours per day unpaid (MoH, 2014)
- Not paid or voluntary, more than 5 hours per week OR 1-4 hours per week which affects their life e.g. financially or emotionally (Macmillan, 2011)
- Generally close family member and self-identified
- Co-ordinates and delivers care and support for the patient at all levels of need

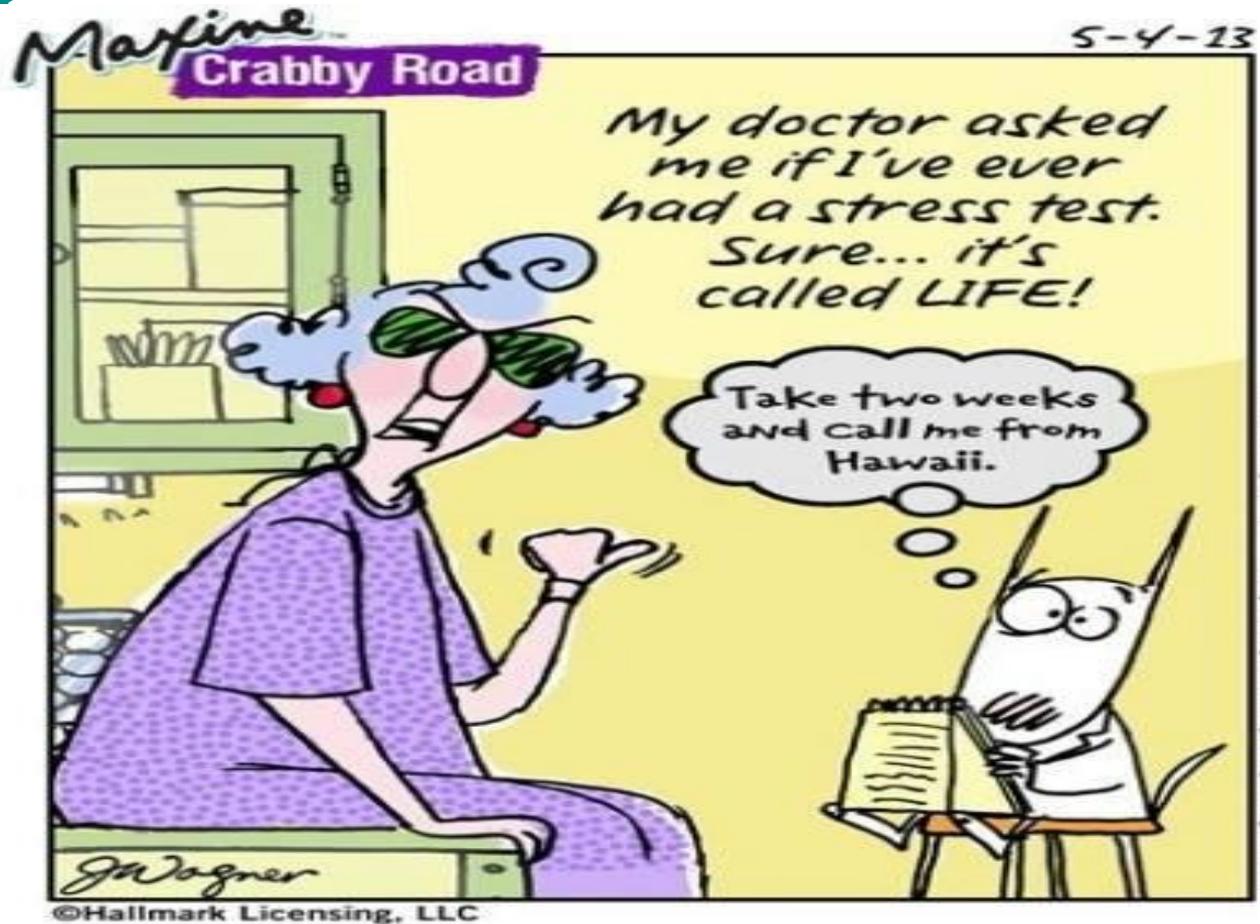
What are the unmet needs of carers?

- A carer's psychosocial welfare is linked in symbiotically with the patients (Keller & Henrich, 1999)
- Have not received social scientific attention (Soothill et al., 2001)
- Will vary depending on:
 - Stage of diagnosis and treatment
 - Stage of life cycle
 - Current socioeconomic circumstances
 - Emotional and physical factors

What is the experience of carers?

- Guilt, anger, sadness, scared, loneliness
- Unpredictability of the future/uncertainty
- Loss of control
- Information needs
- Changes to own identity and social self, relationships and social networks, how others see them
- Tiredness, stress, strain of caring
- Unable to balance their own needs

What are the unmet needs of carers?



Helping to meet these needs

- Needs to differ from psychosocial care offered to patients
- Need to be set in the context of the carer
- Needs to offer strategies to manage demands of role

(Chambers et al., 2011)

Support groups

- Improve emotional and physical functioning, relationships, role adjustment and quality of life
- Offer mutual support
- Increase feelings of competence, equality, social usefulness, and social value
- Decrease stress, anxiety and depression
- Improve coping
- Offer information
- 'Offer a safe place'

**I keep
hitting
'escape,'
but I'm
still
here.**



'Star Supporters'

- Specific needs recognised for carers of haematology patients
- 'Star Supporters' established
- Held at Midland office (Hamilton)
- Initially invited via patient support group mail out and health professionals
- Facilitated by Support service coordinator and counsellor
- Nine attendees

Feedback

Six Questionnaires returned

- Comments made include -

“so nice to talk about what is happening to me”

“I felt safe to talk freely”

“I'm normal, so good to hear others feel the same as I do”

“Its ok to be angry”

“I didn't need to be brave for one afternoon”

“no one judged me”

'Star Supporters' next steps

- Held 3 monthly in Hamilton
- Piloted in Auckland
- Future exploration of support for carers other than spouse (including young carers), and gender, age, stage of disease and cultural variations in support needs

Conclusion

- Through role as SSC identified specific needs of carers of haematology patients
- Support group identified as appropriate way to address needs
- Pilot group of carers was a success and the aim is to expand the Star Supporters across the country

Thank you

- The Carers
- Lyn - counsellor
- Leukaemia & Blood Cancer New Zealand -
Support Services Team
- NZNO
- Rebecca Weeks

References

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