



# LEUKAEMIA & BLOOD FOUNDATION

- Why did we decide to do the research?
- What did we learn?
- What implications does this have for us as health professionals?

# INITIATING RESEARCH – WHY?

- To understand the unmet needs of haematology patients and their families, and to give them a voice
- To verify our knowledge and gain insight into the real-life experiences for these people
- To inform our service and align our service provision
- No previous New Zealand research about relocation specific to haematology

# REAL PEOPLE, REAL LIVES

- “It’s sort of like they stop the clock on you.”
- “Ah well, your life certainly is on hold, if not over. I mean, it’s never the same afterwards, that’s for sure, but yeah, the very minimum you’d say was that it was on hold.”
- “Ah, I had no idea what the hell was happening, I actually went and I had no idea, actually no idea whatsoever.”
- “No, not a clue, eh. I just had to pack up and go.”

# THE REALITY

- The massive stresses placed on families when a person has to relocate for specialist treatment are underestimated
- We need to be aware of the impact on every aspect of life for both the patient and their family members, including those left behind
- Haematology patients are unique:
  - Immediacy of treatment
  - Length of stay
  - Fewer treatment centres for intensive treatments

# THE REALITY

- Both types of relocation
  - ‘accommodation-based’ relocation
  - ‘travel-based’ relocation
- We need to be
  - Empathetic
  - Highly aware
  - Educated about resources available
- Care needs to be continued back home as well
- Kiwis are very stoic & staunch – ‘she’ll be right, mate’

# ACCOMMODATION-BASED RELOCATION

- Need to care for those back home as well as those travelling
- Ensure patients and family members are aware of entitlements
  - National Travel Assistance
  - WINZ
- “Yes, that was difficult, being up there for so long and just the experience of transplant, yeah, it was quite an emotional ride.”
- “It was harder for the ones left at home. Not the sort of holiday you’d choose.”

# TRAVEL-BASED RELOCATION

- It's still relocating, even if perception is short periods of time
- Long hours in the car very tiring
- Families often bear extra expenses and hardship to allow extra time together
- "There were times when [participant's husband] did the two hour round trip twice daily to take me home because I was desperate to be there, rather than in hospital. There's nothing like being in your own home."
- "It's just the journey you take and it's got to be fine and not be an issue so it's not – two and a half hours drive, it's not a biggie, really."



# NATIONAL TRAVEL ASSISTANCE

- [“Were you eligible for the NTA scheme?”] “No, is there one?”
- “We’d looked into it but we aren’t far enough away to get any money.”
- “We did get money back from the government and we were more than appreciative.”
- “If they [family] were travelling with me they got reimbursed for fuel but if they’re travelling on their own they don’t. Obviously most of the time they’re travelling on their own because I stay over there and that was the biggest cost and hassle.”

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- We can 'plug the gap' in many circumstances
  - Providing support and contact in the community
  - Bridging gaps in information
  - Creating relationships with other families
  - Helping with emergency financial assistance

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- “I’m really happy, we’ve been in contact quite a bit. And I think they did a great job with a limited amount of resources.”
- “Any question you can ask them, they’ll tell you. If they don’t have it [information] they’ll find someone who does.”

# A Guide for Carers

He Aratohu mā ngā Kaitiaki



Practical help for people caring for family or friends who are older or have ill health, a disability or a mental health, alcohol or other drug issue.

[www.carers.net.nz](http://www.carers.net.nz)

## THE NEW ZEALAND EXPERIENCE OF RELOCATION FOR TREATMENT FOR HAEMATOLOGICAL MALIGNANCIES

### EXECUTIVE SUMMARY

Patients diagnosed with haematological malignancies require treatment in specialist hospitals. Those living in areas distant from treating hospitals have to relocate for specialist care, and thus deal with the crisis of diagnosis and treatment away from the comfort of home and family. Research indicates that the process of relocation exacerbates the stress of treatment and creates significant practical, emotional, social and financial disruption to the families involved. Individuals are forced to put life "on hold" and negotiate the unfamiliar world of a specialist hospital at a time when they are experiencing the shock of dealing with invasive treatments and the loss of close contact with their supportive network.

The present study, a collaboration between the Leukaemia & Blood Foundation (LBF) and International Program of Psycho-Social Health Research (IIPP-SHR), documents the experience of relocation for specialist care from the perspective of patients and their carers living in New Zealand. Using a qualitative design, the research explored the emotional, social, financial and practical aspects of relocation. The research contributes seminal knowledge and understanding associated with the experience of relocation for patients diagnosed with a haematological malignancy and their carers living in New Zealand, with a hope to inform health policy and service delivery for haematology patients and their families.



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*Vision to Cure - Mission to Care*