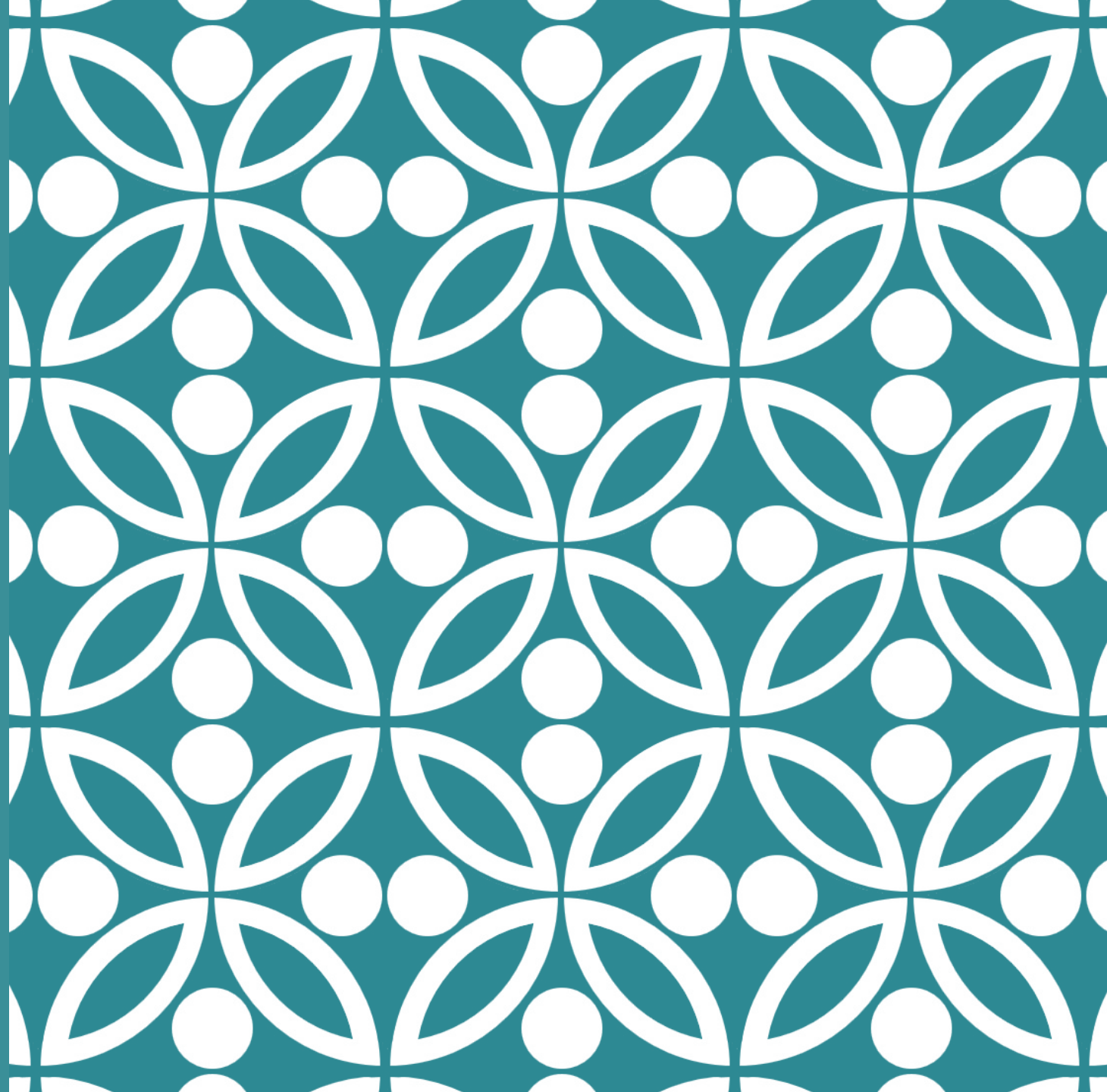


THE PATIENT EXPERIENCE OF ADDISON'S AND ADRENAL CRISIS

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CNSSNZ Conference 2023



BACKGROUND

- Addison's rare endocrine condition that requires life long steroid therapy.
- No literature of studies conducted on the NZ Addison's patient experience was able to be located
- Research question: 'What are the patient's experience of Addison's and being hospitalised with an adrenal crisis?'



RESEARCH PROCESS

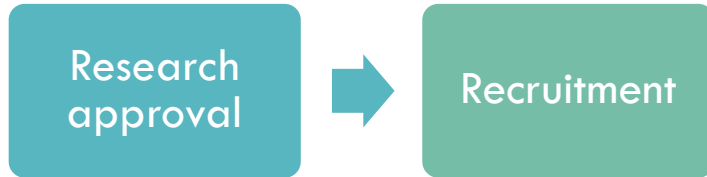
Research
approval

STUDY DESIGN

- Qualitative study
- Interpretive Phenomenological methodology
- Semi structured interviews ($n=6$)
- Participant recruitment conducted via the RED Registry

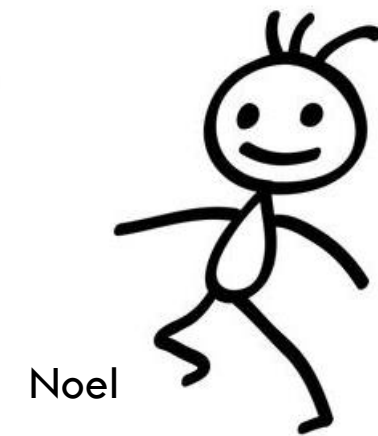
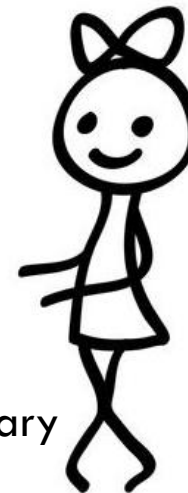
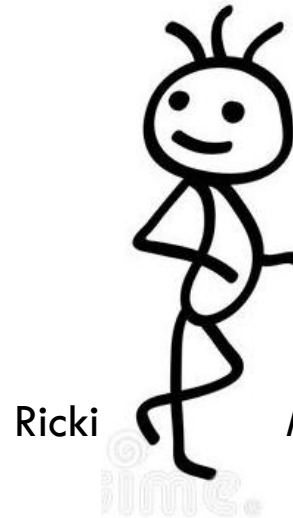
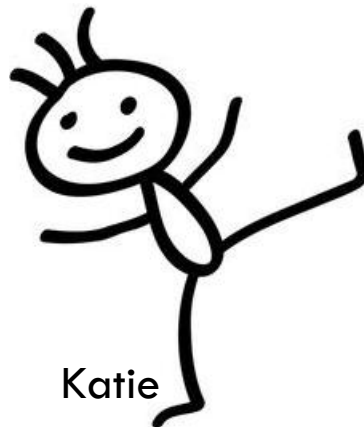
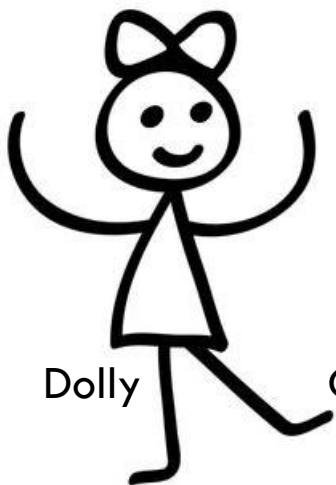


RESEARCH PROCESS



STUDY PARTICIPANTS

- Six participants (3 female: 3 male)
- Age range from early 20s to over 65 years
- Participants identified 23 crises with 15 resulting in hospitalisation
- All of European decent



RESEARCH PROCESS



KEY THEMES IN INTERVIEWS

- Addison's diagnosis
- Adrenal crises
- Steroids
- Hospitalisation
- Education
- Endocrine support

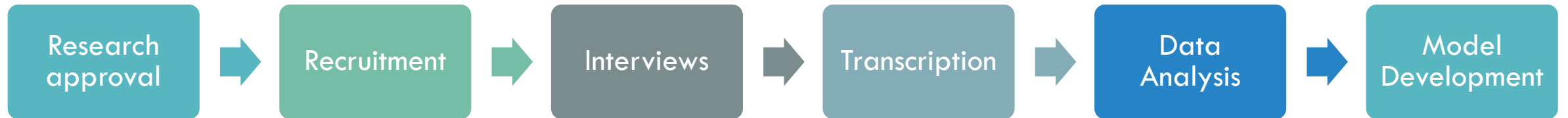
RESEARCH PROCESS



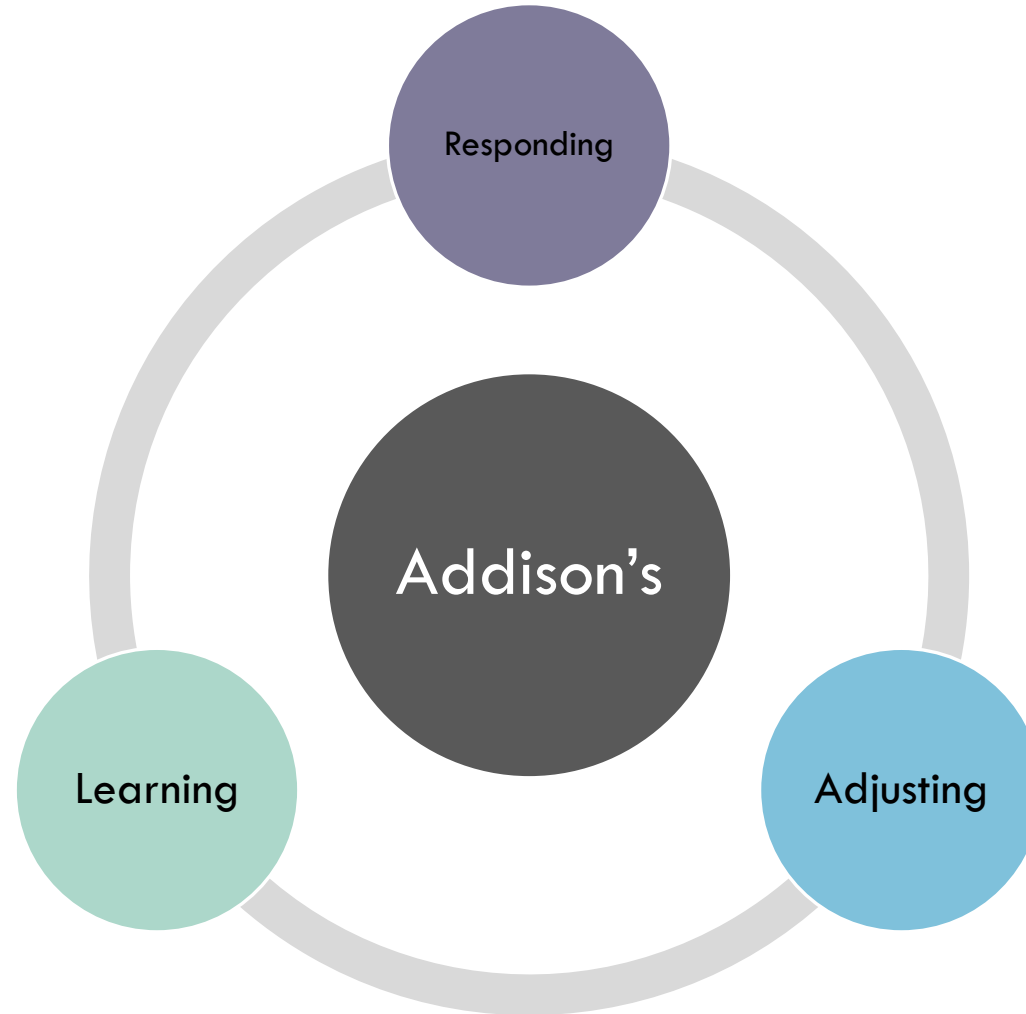
FINDINGS

	Theme	Sub-themes
Addison's	Responding	Recognising
		Intervening
		Reacting
	Adjusting	Normalising
		Promoting self-management
	Learning	Understanding
		Balancing
		Collaborating

RESEARCH PROCESS



PATIENT EXPERIENCE MODEL



RESPONDING - RECOGNISING

"Being tired..., being weak... I think he had noticed the colour of my skin...he [Doctor] looked at the palms of my hands which we thought was kind of weird...this is such a gradual thing that I just had no energy for life" - Charlie

Addison's

"It wasn't really until my skin tone started changing. That's when people started picking up on it" - Katie

"They have been a few situations where, ... I have-have kind of jokingly called it a bit of a yellow alert" - Charlie

Adrenal Crisis

"I don't know if it was actually adrenal crisis or if it was just me being sick and then my Addison's made it worse" - Katie

"My body actually tells me that I'm having a little mini crisis...if I take that four extra [hydrocortisone], and then go to bed and sleep ... then I'm right as rain the next morning" - Noel

RESPONDING - INTERVENING

“One time she did collapse on me... just yelled out “She’s dead” before you knew it there were 5 doctors, and she was thrown up on the bed, she’s got Addison’s, and you know, she needs injection and that’s what you get...we sort of thought oh my goodness can we just have a mark on her name that sorts to see Addison’s 20minutes, I don’t know if its 20 minutes bit it’s the kind of the panic we felt” - Dolly’s Daughter



ENDOCRINOLOGY TO THE RESCUE!

“No one really told me what was going on. I didn’t know if it was something that I had done wrong. I didn’t know like what brought it on. I didn’t know if I was just sick. I don’t even know if they knew, no one really kind of. I don’t really know if [emergency department] even actually spoke to endocrinology either” - Katie

RESPONDING - REACTING



"I was crook, really crook. I take extra hydrocortisone but nothing I forgot all about the injections" - Noel

"No" - Katie

"I guess being a typical pig-headed kiwi bloke, probably always avoided getting jabbed with the needle even though I always had the intravenous cortisol [at hospital]" - Ricki

"It hit you pretty quick too. Like it's not like you can say, "Ah here we go again. This is going to be it" ... it feels almost like a roll of the dice and when it goes that way, it feels like it [adrenal crisis] comes on pretty quickly and there's not much you can do about it. By the time you're in that state, it's too late to really try to react" - Ricki

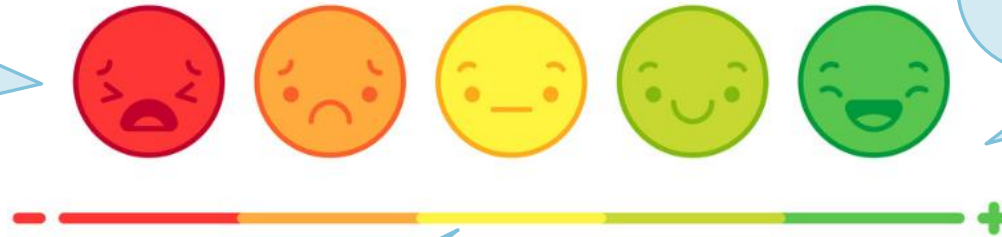
"The more crises I had and the more admissions I had and knew that once I had been on the drip, and had all that stuff [steroids and intravenous fluids] I felt better. I was quicker to... want to go to the hospital...I just want to get the cortisol and feel better...you know instead of in the beginning I'd sort of leave it a few days and then go to help" - Mary

ADJUSTING - NORMALISING

"When I first diagnosed I was really mad. I was like, why the heck is this happened to me and so like I kind of just didn't really listen much I kind of got it I got to take this and this and this" Mary

"I didn't find that a particularly strange issue or anything. I have no problem, with doing that, taking the steroids" Ricki

"The trick is because the treatment is relatively straightforward. I mean like having to take pills two to three times a day, but you know it's liveable. There are no real problems or constraints otherwise" Ricki



The doctor said "You've got Addison's disease and I've been in touch with the specialist in the endocrine department he's given me permission to offer you prednisone for the night and I was just better" Dolly

"I've just accepted that I have Addison's and there's somethings I can do some things I can't do just go on with life" Noel

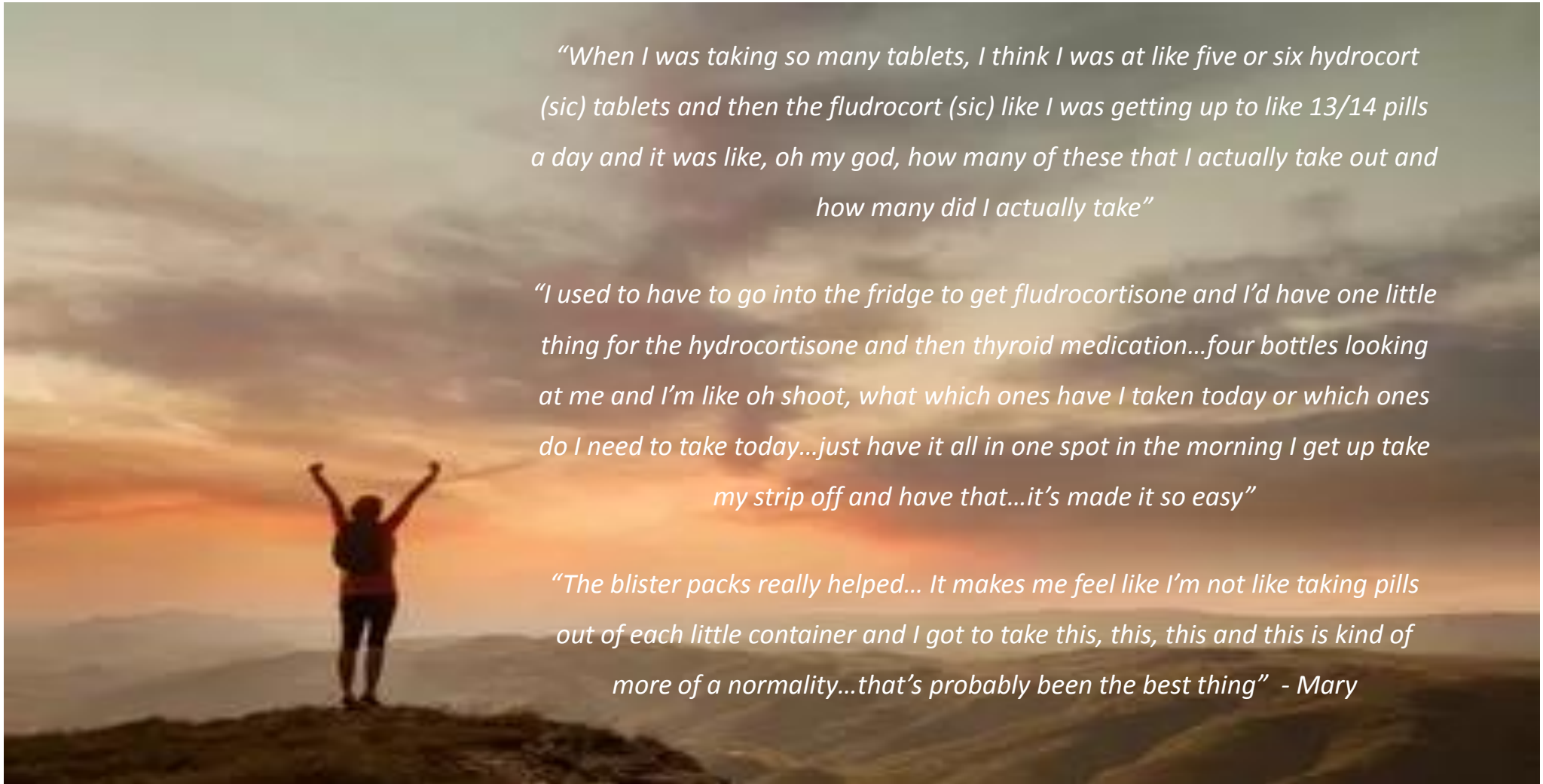
"The diagnosis itself, I can only really see as a positive thing...from all points of view... getting home from work and actually, wanting to have a conversation, not just you know, have some food before sleep. Um, it's been, pretty fantastic" Charlie

ADJUSTING — PROMOTING SELF MANAGEMENT

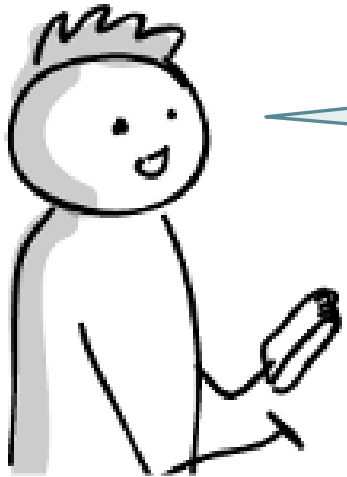
“When I was taking so many tablets, I think I was at like five or six hydrocort (sic) tablets and then the fludrocort (sic) like I was getting up to like 13/14 pills a day and it was like, oh my god, how many of these that I actually take out and how many did I actually take”

“I used to have to go into the fridge to get fludrocortisone and I’d have one little thing for the hydrocortisone and then thyroid medication...four bottles looking at me and I’m like oh shoot, what which ones have I taken today or which ones do I need to take today...just have it all in one spot in the morning I get up take my strip off and have that...it’s made it so easy”

“The blister packs really helped... It makes me feel like I’m not like taking pills out of each little container and I got to take this, this, this and this is kind of more of a normality...that’s probably been the best thing” - Mary



LEARNING - UNDERSTANDING



What do you remember about your steroid education?

"I was too intimidated and too scared to ask because was so scared of that doctor" - Katie

"Absolutely nothing... Sometimes I think a refresher would be good" - Katie

"Sometimes knowledge is good...no nobody has sat down and told me why I've got Addison's" - Noel

"I don't really remember much. I think I've learned more and more as it's gone on." - Mary

"It was definitely a little bit of a crash course. It was just take these pills and everything should kind of be okay...I definitely was given the intravenous cortisol to take with me in case of emergency. Maybe not particularly well educated about how to inject it...there was a session but definitely could have been a little bit more detail around that...made it maybe a little bit less scary in terms of trying to avoid it" - Ricki

"No I haven't had any education about my steroids at all" - Noel

LEARNING - BALANCING

“For 45 years, I’ve had 20mgs of hydrocortisone in the morning, and 5mg at night. Now I have laid over 1000 bricks that a day on that. When I came here and they changed it. Everything went to pot” - Noel



“You’ve got bloody one and half tablets in your lunchbox or in you know they smashed they fall apart and then suddenly ran out of pills, you got 100 of these and none of those” - Noel

“I started off with taking everything in one go first thing in the morning and that was it. It was just one dose” - Ricki

“I’m not sure that I really noticed a big difference. I understand the principle...I’m not going to say I noticed a huge difference to be honest” - Ricki

LEARNING - COLLABORATING

“One interesting thing when somebody said does anyone have trouble using the telephone that they didn’t have before we asked professor [endocrine facilitator] he said no can’t see that being a problem then others turned around and said yes I’m terrified of having to ring up and you know isn’t that odd I get like that” - Dolly



“It’s such a rare thing that you know that there are others out there that have it like there might not be many...I joined on the Facebook is that Facebook Addison’s page...I just felt like a kind of like alien because I was like I’m the only on there’s not many in New Zealand that have it” - Mary

“I had a miracle because somebody told me there was some Addison’s support group in Auckland...People had come from all around the country and the diversity just hearing other people experiences and uh, that was marvellous” - Dolly

IMPROVEMENTS TO PATIENT CARE

- Patient education evening
 - Regular group education sessions
- Steroid card
- Adrenal crisis guideline
- Shared patient list

Te Whatu Ora
Health New Zealand
Waikato

Adrenal Crisis Management

Guideline Responsibilities and

Department Responsible for Guideline

Endocrinology

Endocrinology - Addison's + Steroid Deficiency

Show 25 entries

NHI	Name
Showing 0 to 0 of 0 entries	

Active Patients

Show 25 entries

NHI	Name
Showing 0 to 0 of 0 entries	

Steroid emergency card (adult)

Important medical information for healthcare staff

This patient is physically dependent on daily steroid therapy as a critical medicine. It must **never be withheld or stopped**. Missed doses, or not increasing steroid doses during illness, trauma or surgery, risks adrenal crisis (see card reverse).

Name Jane Doe

Date of birth 01/01/2000 NHI ABC1234

When calling 111 emphasise this is likely adrenal insufficiency/Addison's crisis/emergency and potentially life threatening emergency.

Emergency treatment of adrenal crisis or suspected adrenal crisis

1. Give 100mg hydrocortisone IV or IM injection stat followed by 50mg hydrocortisone IV or IM 6 hourly
2. IV rehydration with sodium chloride 0.9%
3. Treat cause e.g. gastroenteritis

Scan here for further information or search:
www.endocrinology.org/adrenal-crisis

WT139HWF - 07/23

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THANK YOU, CHARLIE,
DOLLY, KATIE, MARY,
NOEL & RICKI THE
GENEROUS
PARTICIPANTS THAT
MADE THIS RESEARCH
POSSIBLE

