> **“Everybody’s different and they all have different experiences”**

Experiences of people with Parkinson’s navigating wellbeing and hope through community engagement

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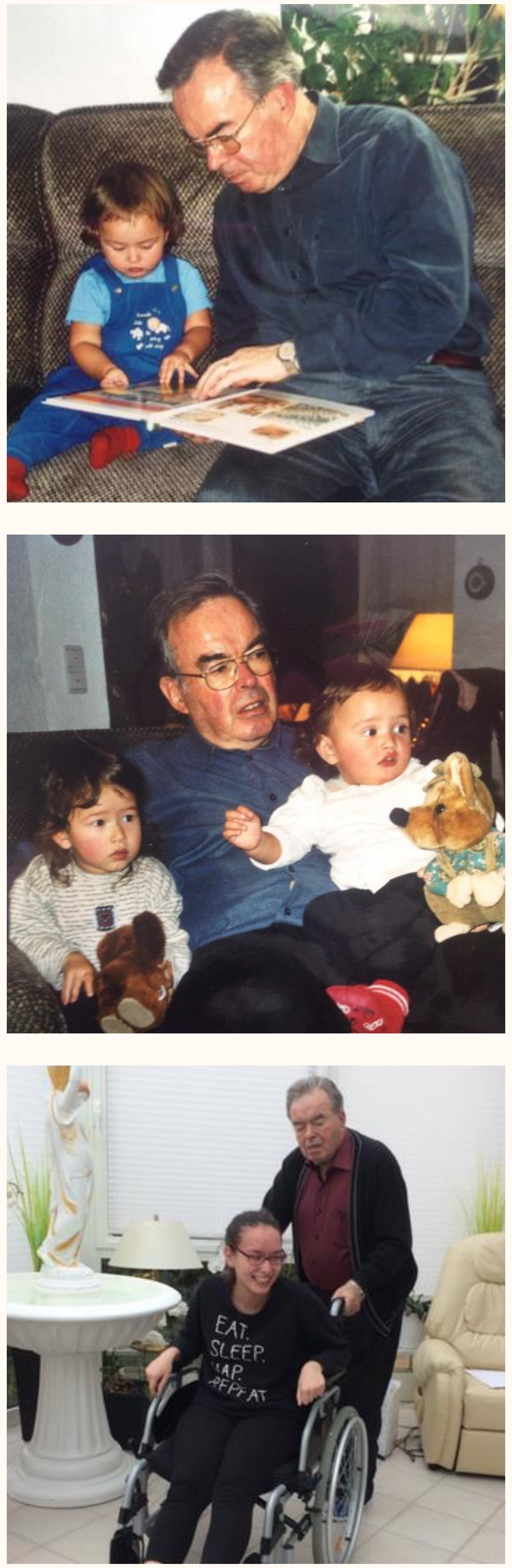

My Positionality

- Diagnosed with Parkinson’s on December 8, 1999, at age 61
- Lived with Parkinson’s for 20 years
- Kept a diary since he was 15 years old
- Never joined a Parkinson’s group
- Hobbies - photography, chess, table tennis, card games, singing
- Was actively engaged in different social and community groups

Background

- Psychosocial dimensions of living with Parkinson’s
- Importance of exercise and physical activities
- Benefits of Parkinson’s-specific therapies and groups
- Physical, social, cognitive and emotional benefits and self-management
- Stigma, social isolation, exclusion, and loneliness on quality of life

What are the gaps?

- Experience of hope and resilience
- The role of community activities
- Experiences adjusting life after a diagnosis
- Navigating information and resources about Parkinson’s
- Responses and coming to terms with a diagnosis

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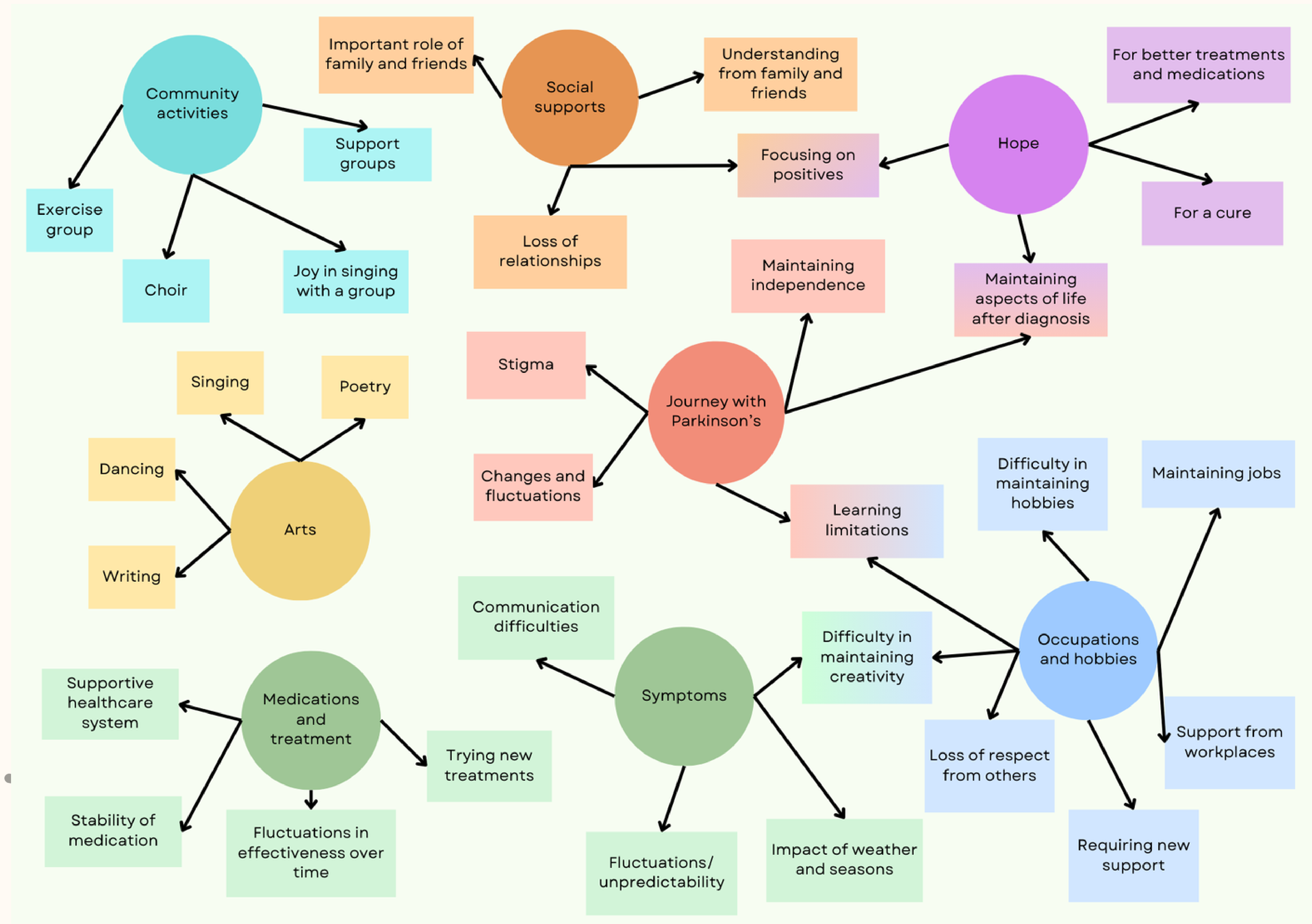
Consultations and topic development

Knowledge Day Exchange 2024



- Community activities
  - Support groups
  - Exercise group
  - Choir
  - Joy in singing with a group
- Social supports
  - Important role of family and friends
  - Understanding from family and friends
  - Focusing on positives
  - Loss of relationships
- Hope
  - For better treatments and medications
  - For a cure
  - Focusing on positives
  - Maintaining aspects of life after diagnosis
- Journey with Parkinson's
  - Stigma
  - Changes and fluctuations
  - Maintaining independence
  - Maintaining aspects of life after diagnosis
  - Learning limitations
- Arts
  - Singing
  - Poetry
  - Dancing
  - Writing
- Occupations and hobbies
  - Learning limitations
  - Difficulty in maintaining hobbies
  - Maintaining jobs
  - Difficulty in maintaining creativity
  - Loss of respect from others
  - Requiring new support
  - Support from workplaces
- Symptoms
  - Communication difficulties
  - Difficulty in maintaining creativity
  - Fluctuations/ unpredictability
  - Impact of weather and seasons
- Medications and treatment
  - Supportive healthcare system
  - Stability of medication
  - Fluctuations in effectiveness over time
  - Trying new treatments

Hope, the arts, and community engagement

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Methodology

- Ten people with Parkinson’s who were in community groups in Tāmaki Makaurau, Auckland
- Semi-structured interviews with optional prop elicitation
- Reflexive thematic analysis (Braun and Clarke)

- Strength-based, holistic approach
- Focus on hope, resilience, lessons and experiences from community activities
- Less focus on lifestyle, medications, possible causes

“Everybody’s different and they all have different experiences”

“you have an incurable disease, and you'll die with it, but not of it.” it's the message you get, and that's pretty crushing

“When I told him about Parkinson's, he said, walk up and down this corridor”

“I just usually call it a chore. I didn’t choose Parkinson’s, Parkinson’s chose me.”

“I go walking because my health depends on me walking”

“You've either got hope or you haven't. Some people have religion. Some people have different views”

“When I think of all that I used to do that, you know, it's shrunk quite a bit”

“that's what brings companionship, the sense of community”

“I felt good when I actually finished doing that, you know, made me feel good.”

“So those things are quite interesting, it gives you hope that they're definitely, you know, working on it”

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MY LIFE HAS CHANGED QUITE DRAMATICALLY

- **STIGMA AND BEING SEEN DIFFERENTLY**
  - “I thought that if I was not like that, people would judge me as a lesser being”
- **LOSS OF OCCUPATION AND SKILLS**
  - “We don't do half of what we used to do”
- **PARKINSON'S AS PART OF THEIR IDENTITY**
  - “It is the most crucial thing in my life”
- **SELF-CARE AND LIVING WELL WITH PARKINSON'S**
  - “You can lead a pretty normal life”
- **ACCEPTING LIMITATIONS**
  - “I have to limit or realize my limitations”
- **ROLE OF MEDICATIONS**
  - “I'm sort of ruled a bit by when I'm “ON””

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JUST DON'T SIT AROUND. IF YOU CAN, DO SOMETHING TO SLOW IT DOWN

DOING THINGS YOU ENJOY

"Anything that you do, that you can find a bit of passion for or enjoyment from"

RECOGNIZING BENEFITS AND IMPORTANCE OF EXERCISE

"“I go walking because my health depends on me walking”"

BEING PROACTIVE

"It's up to you to get off your own butt and do it. No one else can do it for you."

SUPPORTING SELF-MANAGEMENT

"I'm proud. The fact that I've actually done"

COMMUNITY THINGS THAT KEEP US SORT OF TOGETHER

BEING PART OF DIVERSE, MIXED GROUPS

> “The real community of people here”

MAKING CONNECTIONS WITH OTHERS

> “That's what brings companionship, the sense of community”

GETTING SUPPORT FROM OTHERS WITH PARKINSON'S

> “Helps understanding that everybody is different”

SUPPORTING WELLBEING

> “They're big part of my social connection”

THERE'S NOT ENOUGH KNOWN ABOUT IT

MIXED EXPERIENCES WITH HEALTHCARE

> [GP] didn't know anything, what to do about it or anything,

LACK OF KNOWLEDGE AND INFORMATION

> It really is quite a difficult thing to pull together all of the strands

BASIC UNDERSTANDINGS AND STEREOTYPES

> I knew the word. I knew that it meant shaking. That's about it.

COMING TO TERMS WITH A DIAGNOSIS

> “you have an incurable disease, and you'll die with it, but not of it.” it's the message you get, and that's pretty crushing

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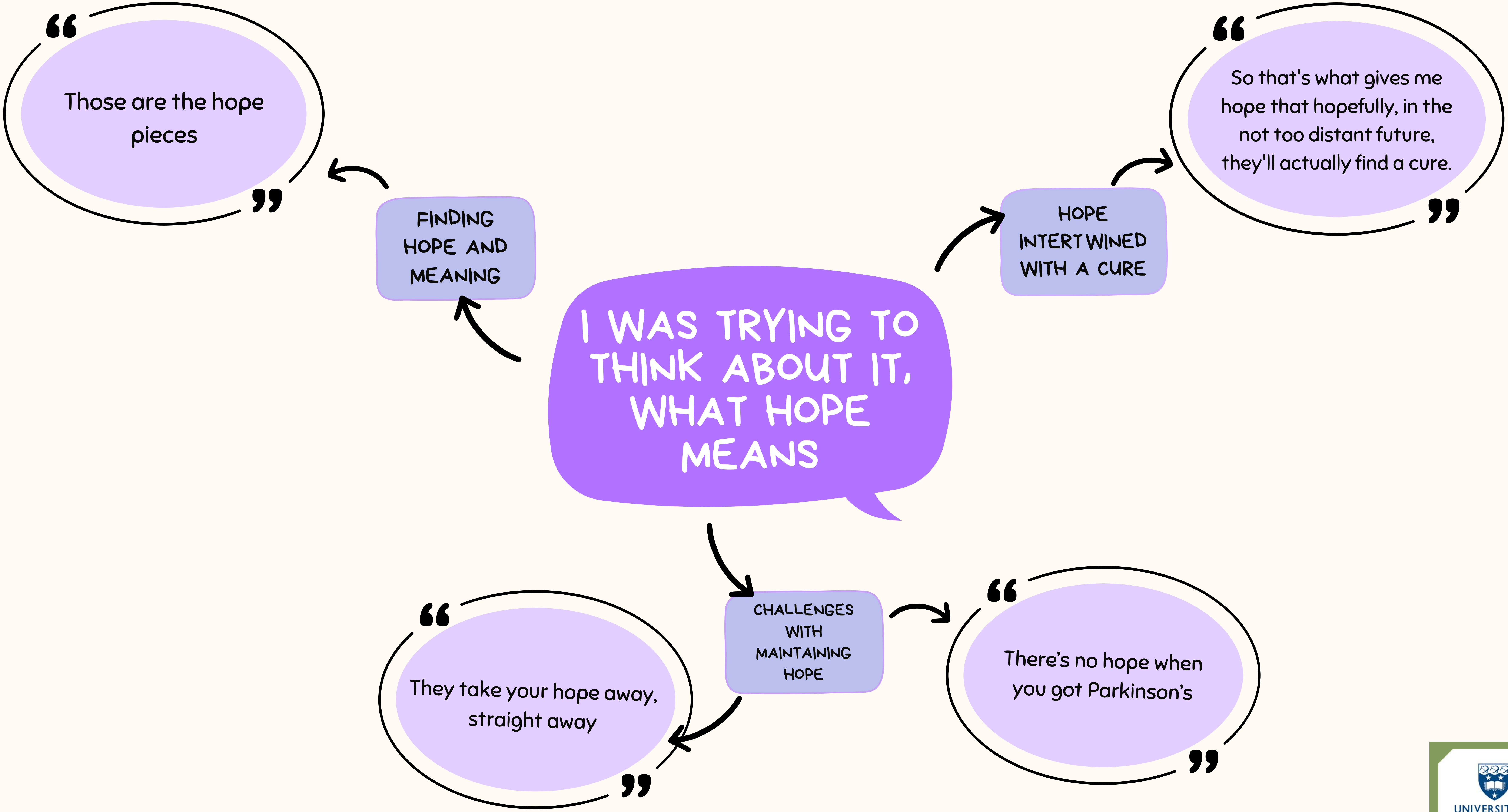

I WAS TRYING TO THINK ABOUT IT, WHAT HOPE MEANS

FINDING HOPE AND MEANING

> “Those are the hope pieces”

HOPE INTERTWINED WITH A CURE

> “So that's what gives me hope that hopefully, in the not too distant future, they'll actually find a cure.”

CHALLENGES WITH MAINTAINING HOPE

> “They take your hope away, straight away”

> “There’s no hope when you got Parkinson’s”

“Don’t kick us away”

Advice to Neurologists and Health Professionals

“Have resources to give to people”

“the lack of information, and it really is quite a difficult thing to pull together all of the strands.”

“include exercise in his presentation instead of saying you've got [Parkinson’s]”

“The variation of the disease...sort of quite complex...Have a better understanding of those conditions”

“To give a diagnosis to this person as though they were giving it to one of their siblings, or one of their children or their partner, and would they say it the same way.”

“I think they have to know of a way to give you the key to finding it out for yourself.”

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“How everyone's different. And every person with Parkinson's is different.”
Messages and advice to others

“We all deal with things differently”

“Because you've got Parkinson's doesn't mean to say, you're going to shake”

“There's more symptoms than just a tremor, visible tremor”

“I actually think I'd like to change what they call it, disease. Disease sounds like you contract something. With Parkinson, you don't contract it, do you?”

“Just treat them as a normal person”

“Treat everyone like you'd like to be treated, and that’s with respect”

“People not realising that you have these limitations and why”

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“Just don't give up hope”

Advice to other people with Parkinson’s

“It's up to you to get off your own butt and do it. No one else can do it for you.”

“Keep on hoping and join a support group”

“Don't give up beneficial exercises because they're really important”

“Start talking to other people with Parkinson’s”

“Whatever exercise you enjoy”

“Join community activities that help you get off the sofa”

“Look for alternatives to Western medicines”

“It's not a death sentence....you can lead a pretty normal life as long as you adhere to the the advice you're given... and yeah, don't panic.”

“It's more getting out and finding what you do like. You don't have to do stuff you don't like... It's more about doing something that you like rather than being artistic or specific. It's more something that really floats your boat.”

“There's lots of resources that you can use these days to make you aware of what what it's all about”

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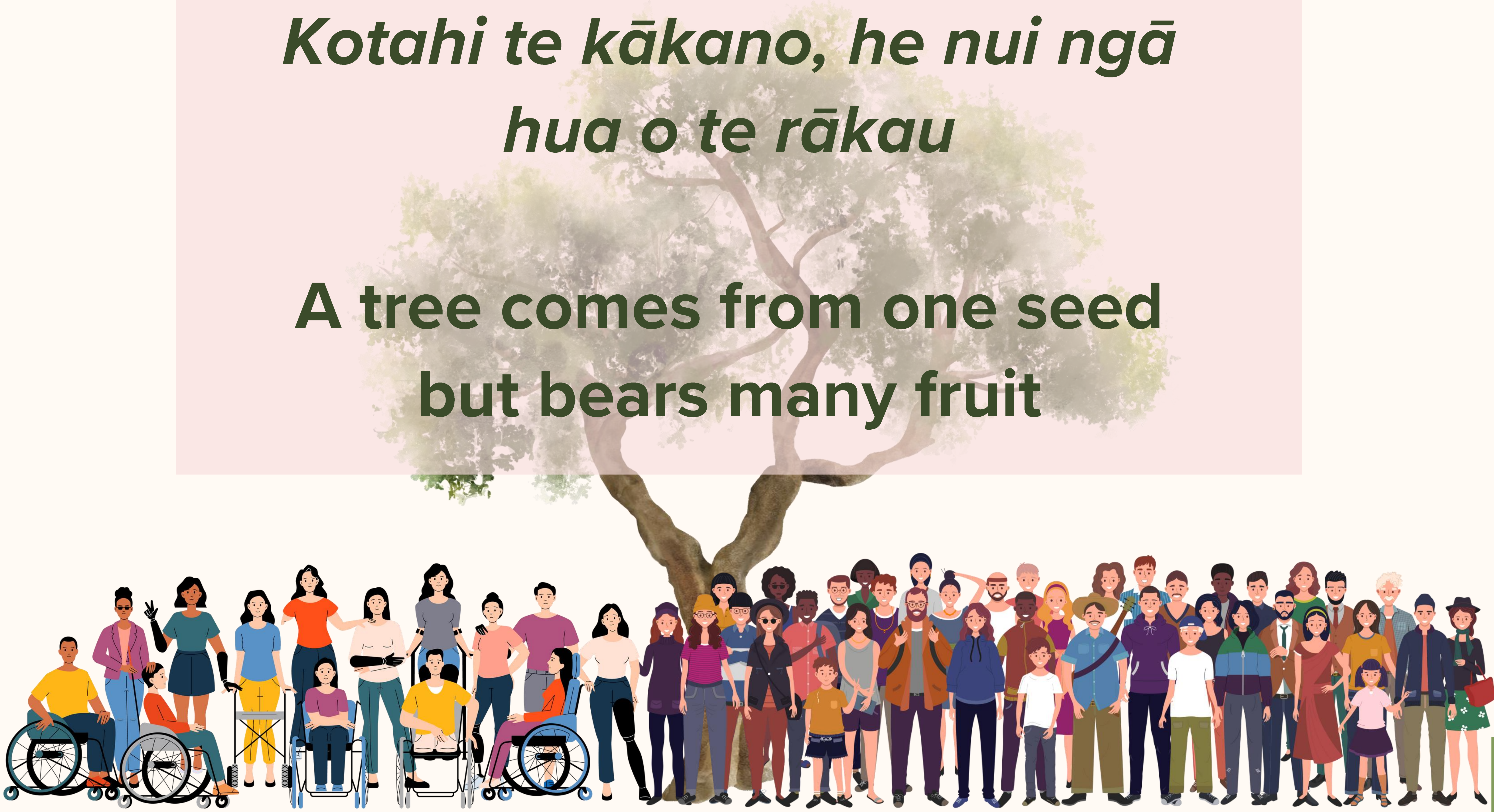
Kotahi te kākano, he nui ngā hua o te rākau

A tree comes from one seed but bears many fruit



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