

The Changing Nature of Hope – A Personal Reflection.

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Introduction

Everyday Usage of the word 'Hope'

- We often tell people not to give up **hope** when they encounter adversity in their lives.
- We **hope** that tomorrow will be a better day.
- We **hope** our children will grow up healthy and be happy.
- We **hope** that our goals and dreams for the future will one day come true.
- We **hope** that, when life takes an unexpected turn, we will find the strength and courage to keep moving forward.



Insights into what 'Hope' means

- **Hope** can coexist with fear and uncertainty.
- **Hope** can change as our condition progresses.
- **Hope** can be strengthened by people who walk alongside you
- **Hope** can disappear when we attach it to one particular outcome
- **Hope** can be renewed when we discover a new possibility or pathway forward
- And sometimes **hope** can be sitting right in front of us without us being able to see it.



The Day my Life Changed



Who I was before my Diagnosis

The Life I Feared Losing

MY IDENTITY

EDUCATOR

35+ years in education
Senior Physics & Chemistry
Teacher
Deputy Headmaster

FAMILY

Husband • Father
Family • Friends

SPORT & COMMUNITY

Swimmer • Surf Lifesaver • Coach
Belonging • Purpose •
Contribution

MY DIAGNOSIS

**I was frightened that
Alzheimer's disease
would take away the life
I had been living —
and the person I knew
myself to be.**

MY HOPE

**I desperately wanted my
old life back.**

I placed my hope in research and
particularly in my participation in
a clinical trial.

**I hoped it might stop the
progression of my disease.**

IDENTITY → FEAR → HOPE



Reframing Hope

From Stopping Alzheimer's to Living With It

MY EARLY HOPE

**"I wanted to become
a survivor of
Alzheimer's
disease."**

I don't think that was naïve.

When my life was full of
uncertainty, I needed
something that gave me back a
sense of control.

WHAT I LEARNT

**Hope can coexist with
fear and uncertainty.**

**Hope becomes
incredibly vulnerable
when you attach it to
only one outcome.**

That realisation changed the
question I was asking myself.

THE QUESTION CHANGED

Instead of asking:

**"How do I stop
Alzheimer's disease?"**

I began asking:

**"How do I want to live
with Alzheimer's
disease each day of my
life?"**

CONTROL → REALISATION → LIVING EACH DAY

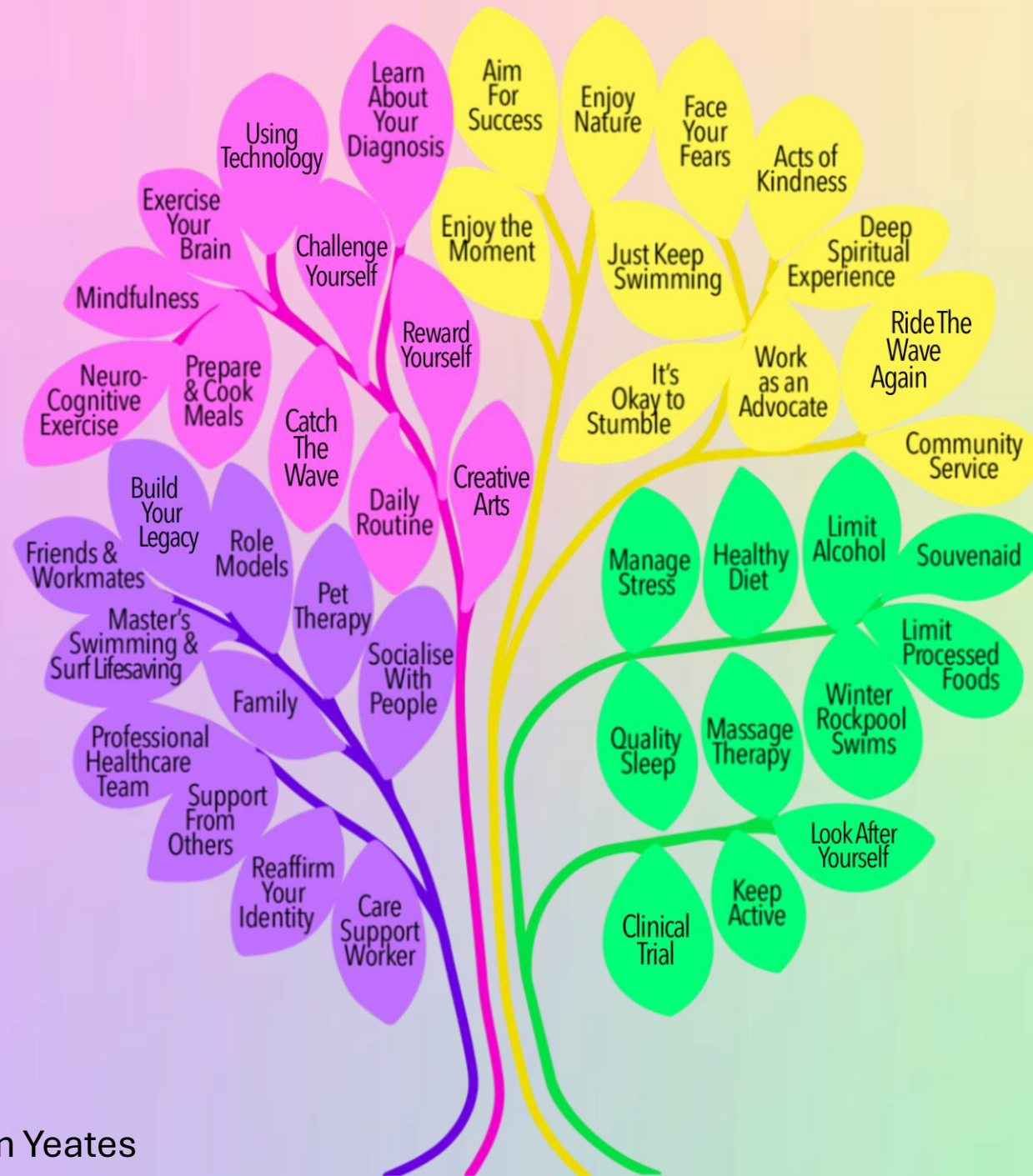


Tree of Awakening your Positivity



Mind

Soul



Heart

Body

Swimming is more than Exercise

Swimming supports my physical health and cardiovascular fitness — but I don't swim every lap thinking about reducing the amyloid in my brain.

I SWIM BECAUSE

I ENJOY IT

I SWIM BECAUSE

IT CHALLENGES ME

I SWIM BECAUSE

IT CONNECTS ME
WITH WHO I AM

Swimming connects me with the person I have always been.

HEALTH → ENJOYMENT → CHALLENGE → IDENTITY



A Different Type of Hope

HOPE BECAME ACTIVE

Hope became less about waiting for something unexpected to happen... and more about recognising the possibilities that still exist around me.

Maintain control where I can

Adapt when I need to

Continue to challenge myself

Invest in what gives my life meaning

OTHERS CAN SHAPE HOPE

Because Alzheimer's affects relationships, emotions and belonging, the actions of people around me matter.

They can strengthen hope — or gradually take it away.

"What you can no longer do"

"What is still possible"

I AM STILL ME

When people...

Involve me
Challenge me
Laugh with me
Ask my opinion
Treat me as an equal

I am reminded:

I AM STILL ME.

POSSIBILITY → CONNECTION → IDENTITY



Walk alongside me

DON'T WALK IN FRONT

**Taking control because
you assume you know
what is best for me.**

Support should not mean making
every decision on my behalf.

DON'T WALK TOO FAR BEHIND

**Leaving me to manage
every challenge alone.**

Independence does not mean I
should have to do everything
without support.

WALK BESIDE ME

Support me when I need it.

**Allow me to retain control
over my own life.**

Understand when to help — and
when to let me lead.

**Hope is strengthened when I remain an ACTIVE PARTICIPANT in my own life — not a passive
recipient of care.**



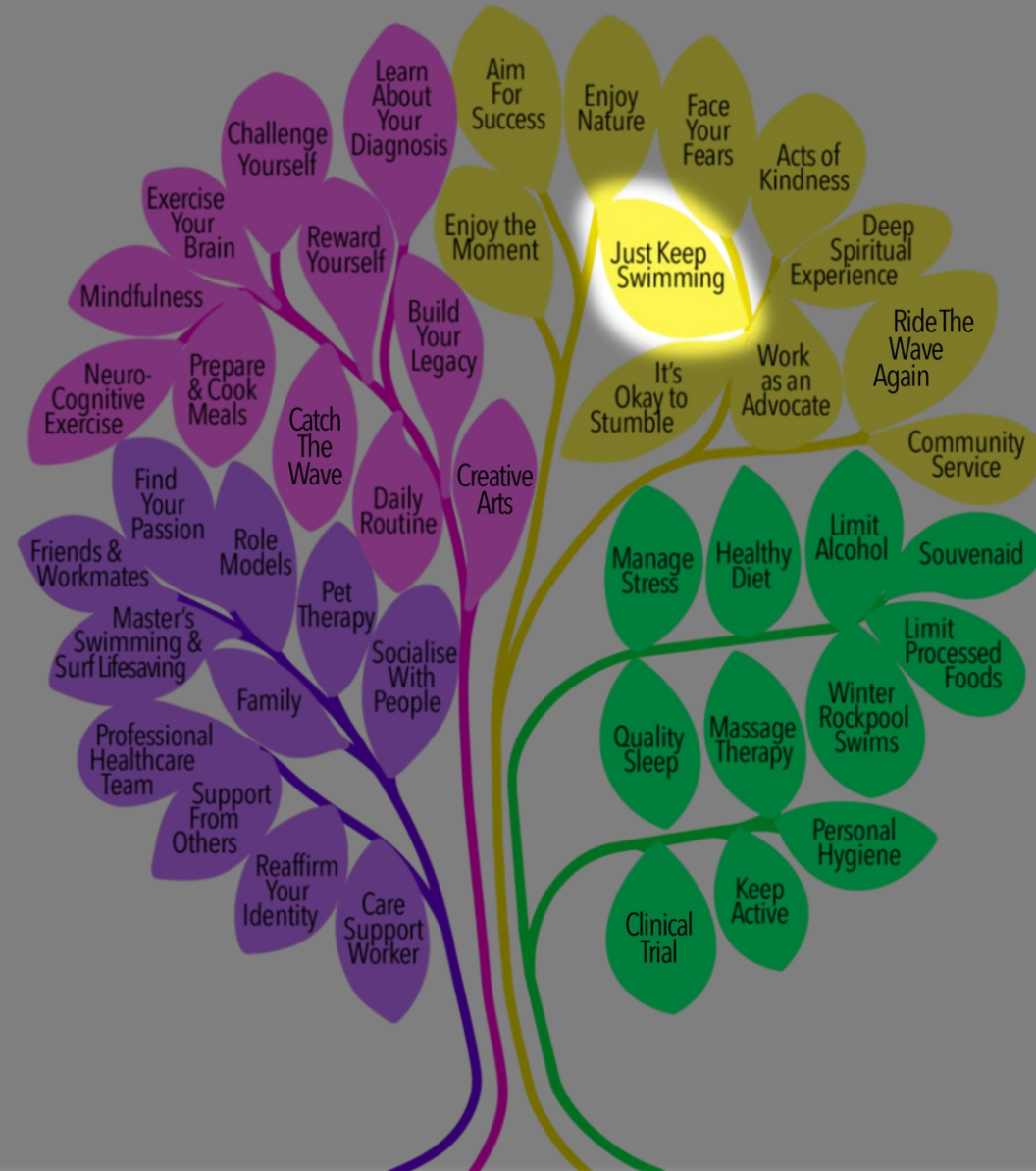
Most Important Leaf

Mind

Soul

Heart

Body



Just Keep Swimming



Clinical Research and losing a source of Hope



Second Amyloid PET Scan

- **Second Amyloid PET scan** on 24 July 2026 – gave me a Centoloid quantisation value of 102 CL
- Report – high degree of binding in the following areas - Frontal, precuneus/posterior cingulate, lateral parietal and lateral temporal cortex and the striatum.
- Highly positive for amyloid is > 80 CL



A Different Interpretation

The scan told me about the pathology — but not the whole story of my life.

WHAT THE SCAN SHOWED

My Amyloid PET scan showed that the pathology had progressed.

Professor Michael Woodward didn't pretend that this was good news.

But he reminded me that a scan tells us something important — not everything about the person.

WHAT THE SCAN COULDN'T SHOW

It didn't show that I had remained:

Physically active

Intellectually engaged

Socially connected

It could not show the travelling, speaking, research, relationships and responsibilities that continued to shape my life.

A DIFFERENT PERSPECTIVE

And suddenly I realised...

I had been looking at what had progressed in my brain —

and had forgotten to look at what had progressed in my life.

**WHERE THE AMYLOID HAD PROGRESSED,
I HAD FORGOTTEN THAT MY LIFE HAD ALSO PROGRESSED.**



Looking Beyond the Result

MICHAEL GAVE ME TWO NEW POSSIBILITIES

OPTION 1 — ANTI-AMYLOID MABs

Designed to remove amyloid from the brain

OPTION 2 — TARGET TAU PATHOLOGY

Clinical trial targeting the removal of tau pathology

THE PATHWAY I HAVE CHOSEN

Neither option offered a cure and both contained uncertainty — but there were still pathways open to me.

UNCERTAINTY — BUT RENEWED HOPE



Conclusion

