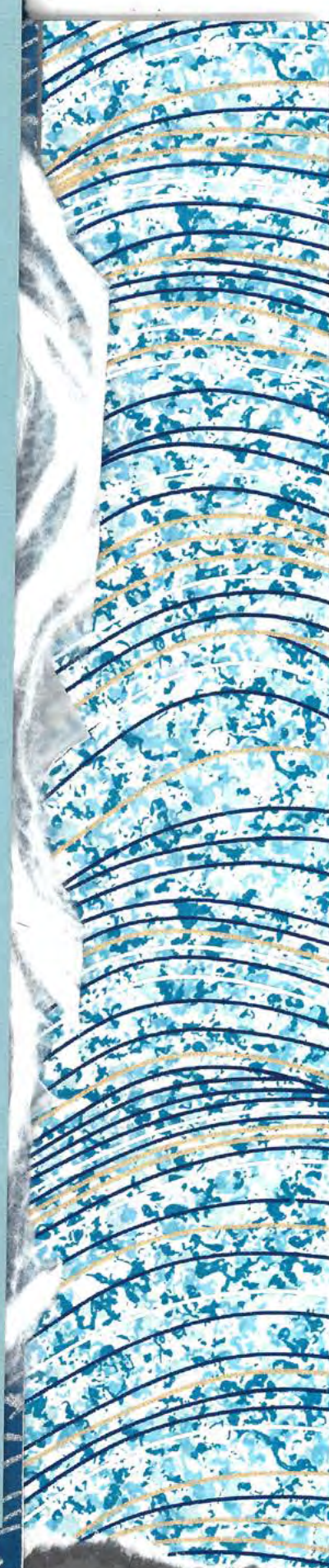


What People Need to Know
About
Dementia Care



From
5 Courageous Care Companions
Experiencing Their Loved One's
Cognitive Change



Five dementia care partners participated in the creation of the text that follows.

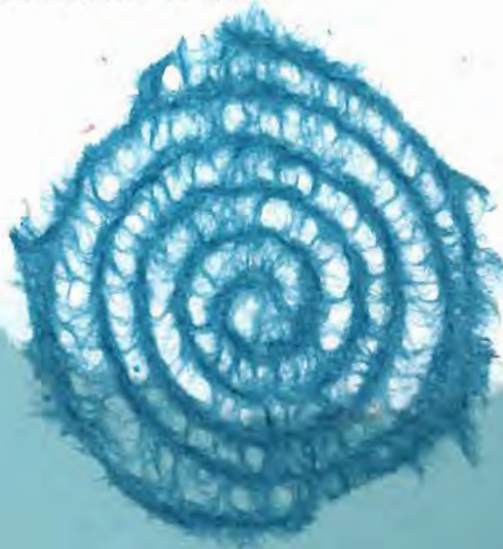
Over the past few years their words of wisdom, flickers of joy and flashes of frustration were collected.

Each reflection, remark or request resonated at a certain point along the course of the disease.

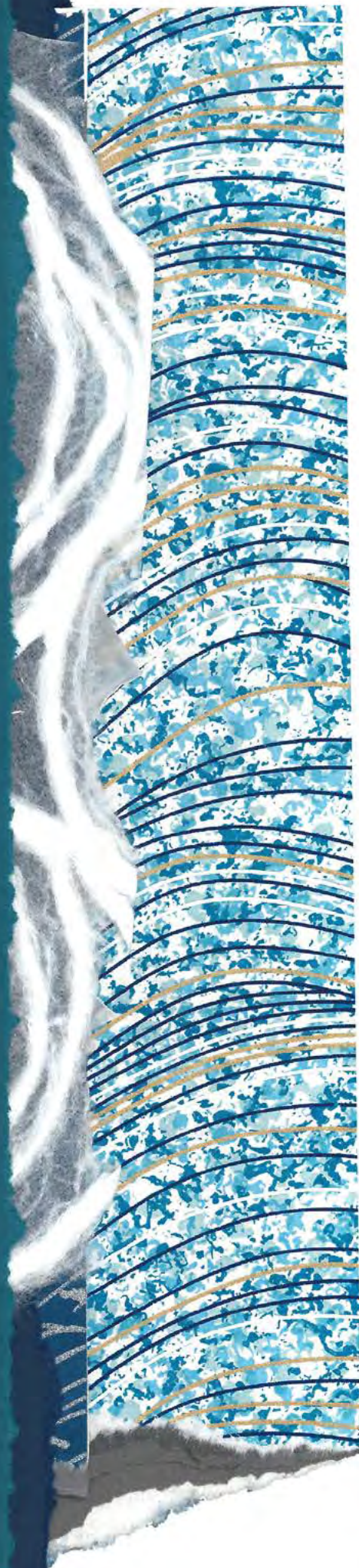
In the winter of 2022-'23 we gathered a selection of these thoughts to bear witness and give expression to the care-partnering experience.

This booklet was inspired by its companion piece: a 2016 booklet of insights and advice from five brave spirits living with early-stage Alzheimer's or other cognitive impairment.

A note on the importance of terminology: we choose humanistic language. For example, we like the terms "care companion", "care partner" or "carer" rather than "caregiver". We grow and deepen through this experience, along with the changing needs of our loved one. There is receiving as well as giving. We remind ourselves that we're in this together with someone we love. Another language choice: we refer to the "course of the disease" or its "development" rather than disease "progression". It's hard to feel any part of this is "progress."



What
we want
you to know
about
living with
our loved one's
cognitive change.



We long for a culture that embraces dementia.

Keep me and my loved one with dementia in your life.

We can't do this alone.

There are endless ways to make a connection:

Send a postcard

Make a phone call

Let us know you are near

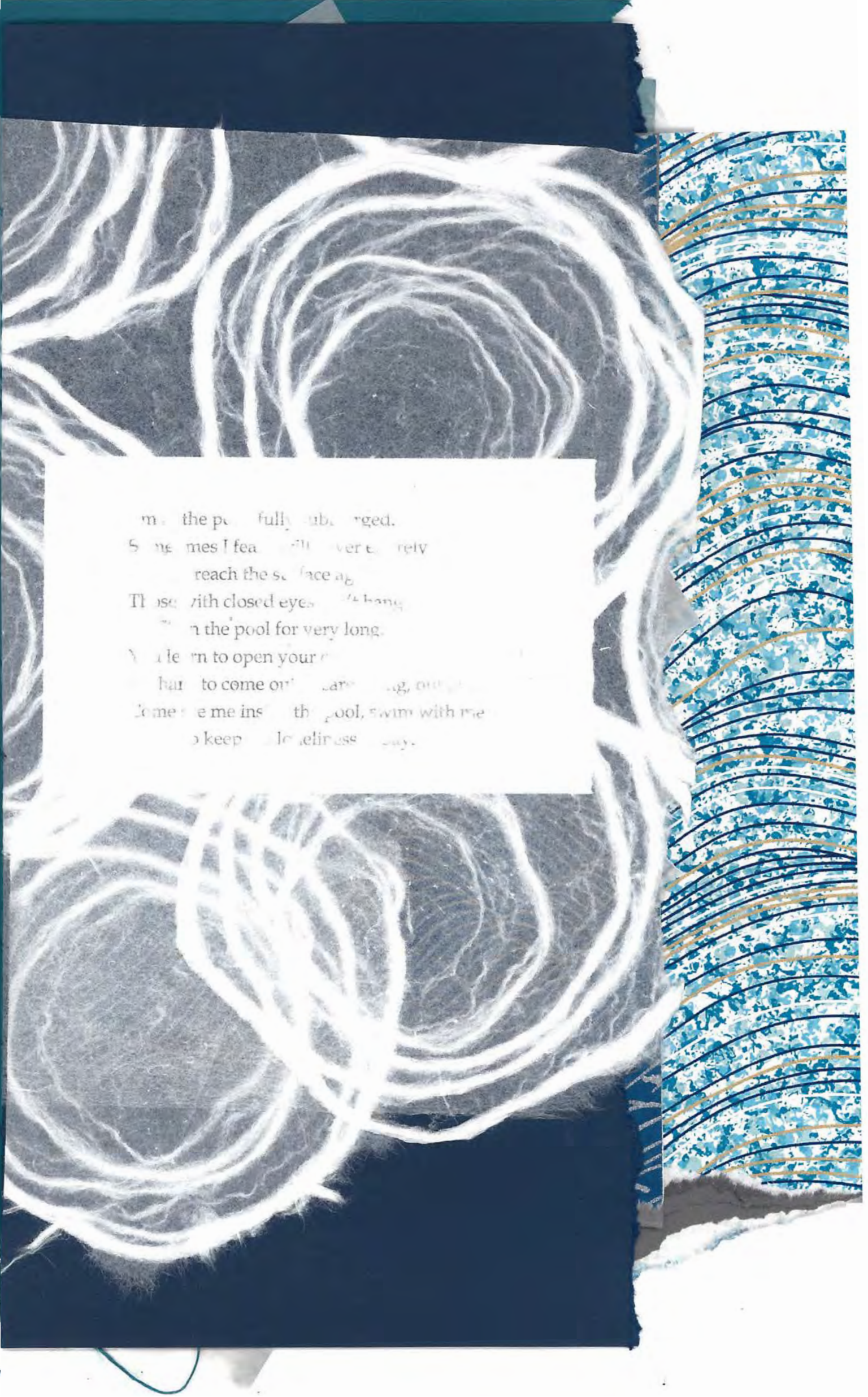
Include my loved one in conversation

Give us flexible options for things to do, times to meet,

without expectations;

understanding last-minute changes.

We need the company and support of others to buoy us.



in the pool fully submerged.
Sometimes I fear I'll never truly
reach the surface again.
Those with closed eyes can't hang
in the pool for very long.
You learn to open your eyes
and bar to come out, and hang, out of
the pool, swim with me
to keep the loneliness away.

We long for a culture that embrace dementia.

Keep me and my loved one valued and present in your life.

We can't do this alone.

There are endless ways to make a connection:

Send a postcard

or make a phone call

Let us know you are near

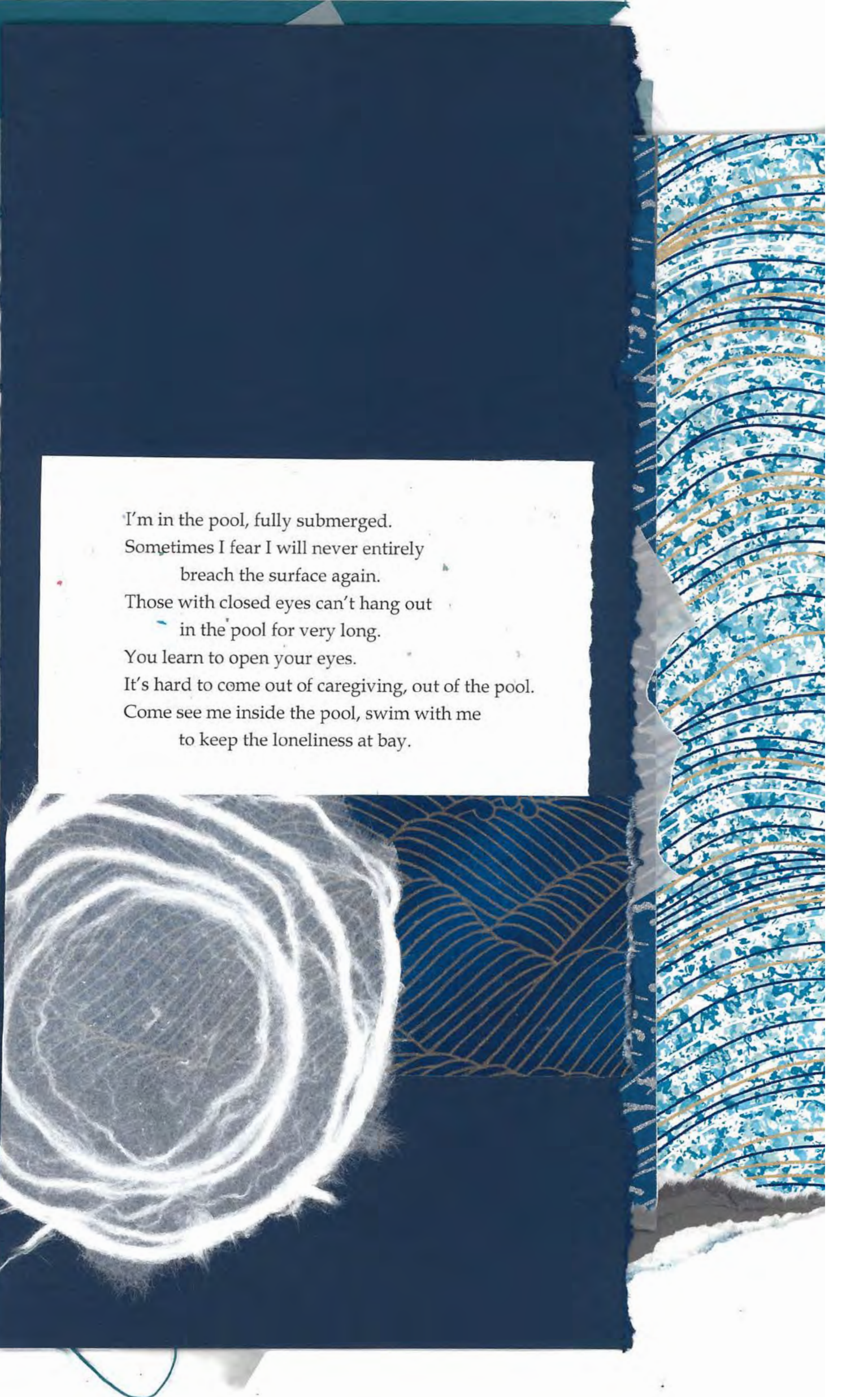
Include me in your conversation

Give us meaningful things to do, time to spend

without expectations;

and understanding with all life changes.

We need your company and support. We need others to build



I'm in the pool, fully submerged.
Sometimes I fear I will never entirely
 breach the surface again.
Those with closed eyes can't hang out
 in the pool for very long.
You learn to open your eyes.
It's hard to come out of caregiving, out of the pool.
Come see me inside the pool, swim with me
 to keep the loneliness at bay.

Don't say to us that "*It must be so hard...*

I could never do what you're doing." NOT HELPFUL

Please don't call us "*saints*" or say we're "*going to heaven.*"

We are flawed human beings
caring for someone we love, doing the best we can.

Don't say "You need to be strong for her."

I know I do...

please be strong for me.

Don't try to "fix" or "solve" this for us.

Do meet us where we are. Try to understand.

Listen.

Be willing to sit in companionable silence.

Just be there.

As you listen, share our tears.


They are another way of expressing love.

Don't expect things to be the way they were.

Do try to be part of our new normal...

and know even that will continue to change.

Don't give up on us.



Water is my texture

weightless

buoyant, breaching

treading huge swells

and breathing under....

Water is my texture

dishes and laundry

and gentle, quiet, loving,

almost reverent shower-chair

showers.

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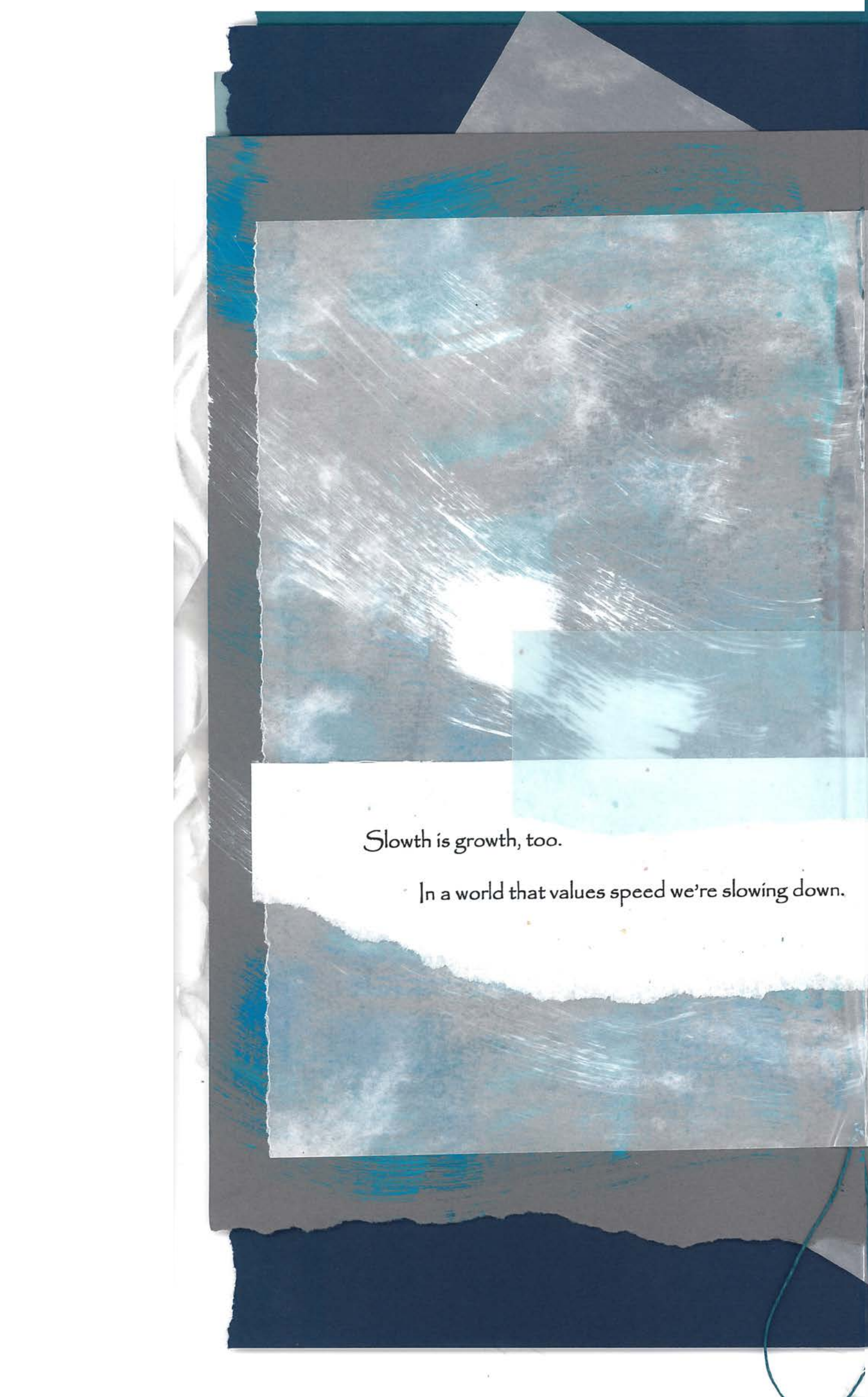
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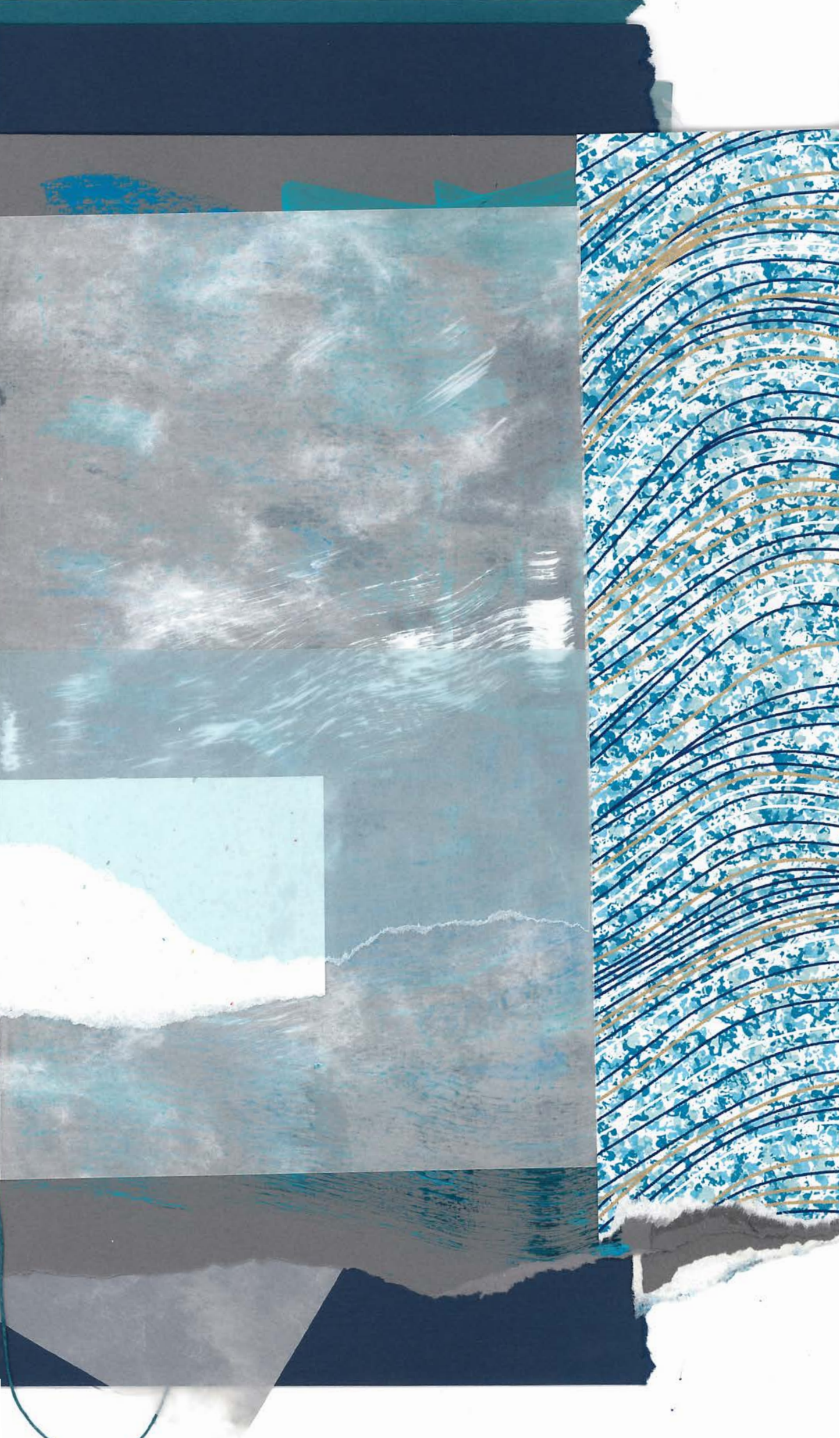
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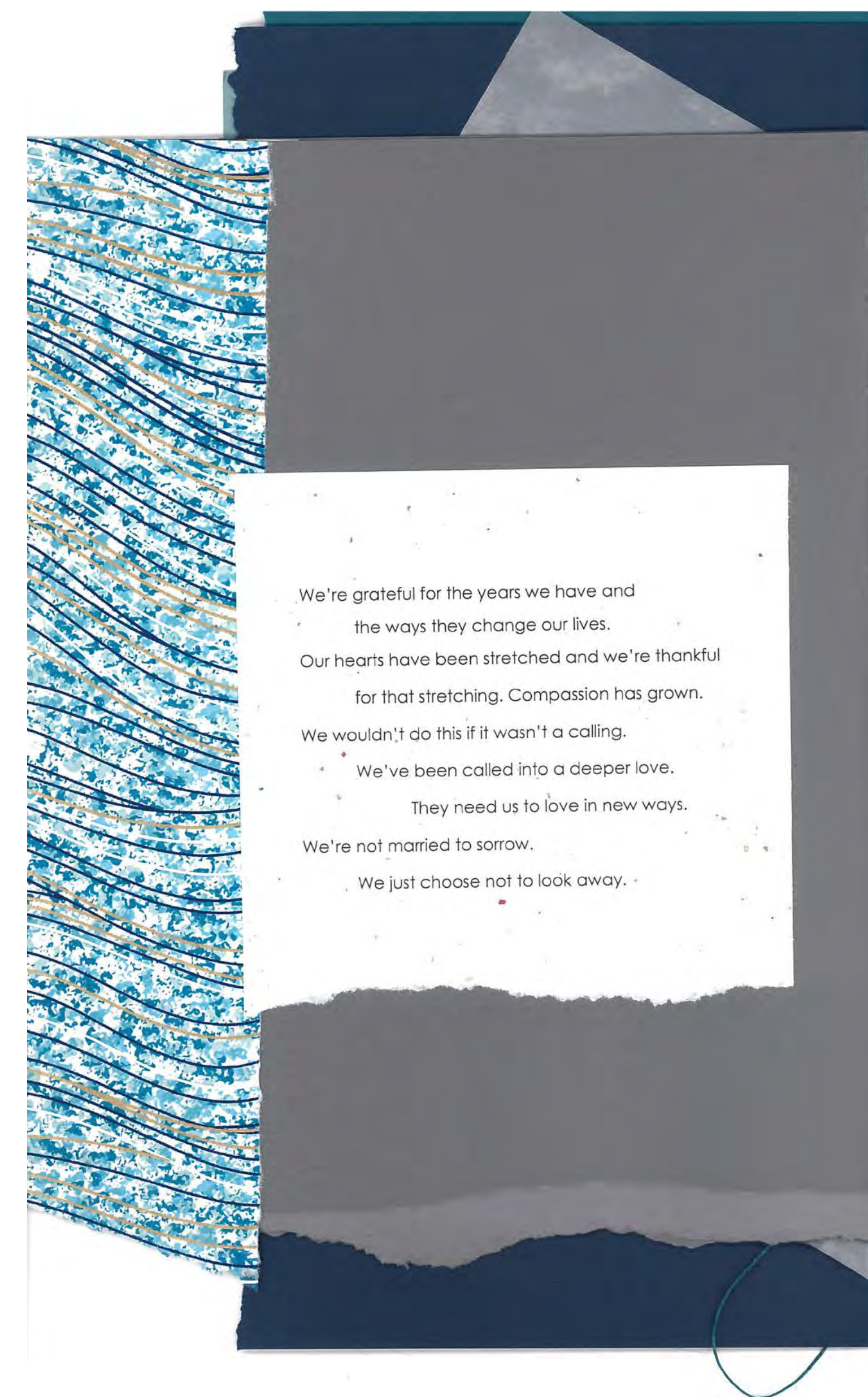




Slowth is growth, too.

In a world that values speed we're slowing down.





We're grateful for the years we have and
the ways they change our lives.
Our hearts have been stretched and we're thankful
for that stretching. Compassion has grown.
We wouldn't do this if it wasn't a calling.
We've been called into a deeper love.
They need us to love in new ways.
We're not married to sorrow.
We just choose not to look away.

Understand there are days our hearts will be broken.

As we care for our loved one, grief is always present.

Grief for what we have lost... and what we will lose.

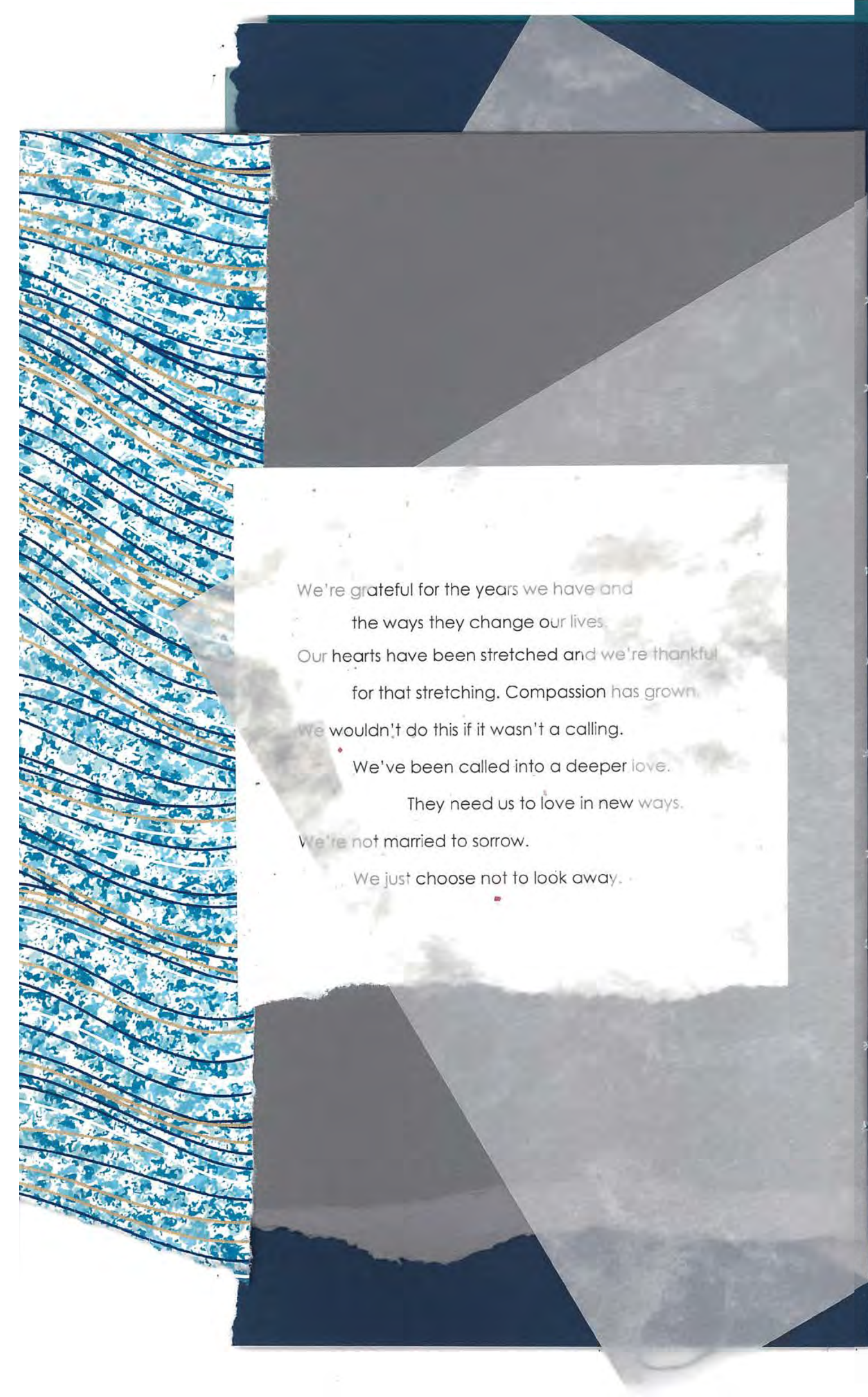
Our hope for is constantly shifting. Joy is relative.

We continually change our expectations.

We might be irritable and snappy. Don't take it personally.

Care partnering uncovers the power of each moment,

love without conditions. Care partners breathe this.



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Care partnering uncovers the power of each moment,

love without conditions. Care partners breathe this.



Grief touches every place, every cell. Like water it changes you.

It's like existing in another substance.

I am mourning

But I will not sink.

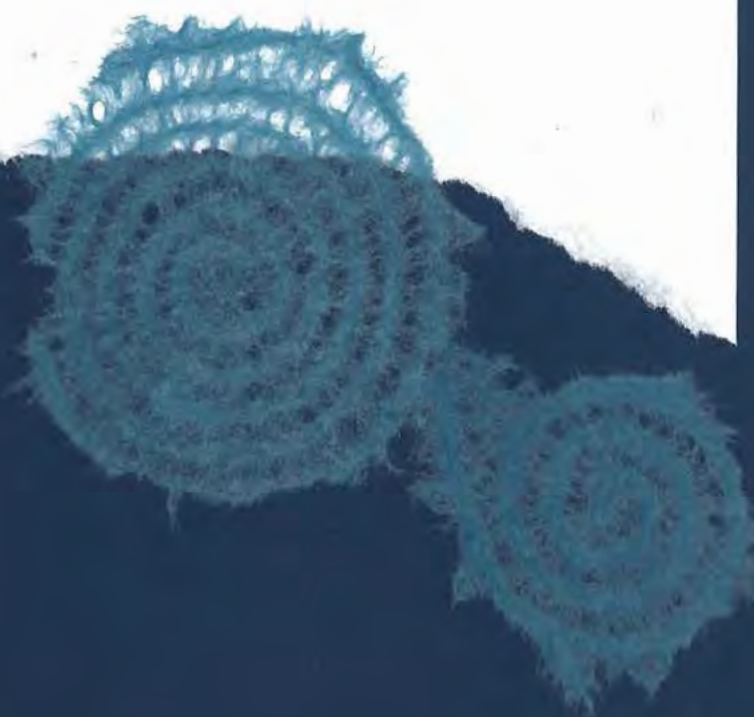
Now I see grief is not an ocean of sadness

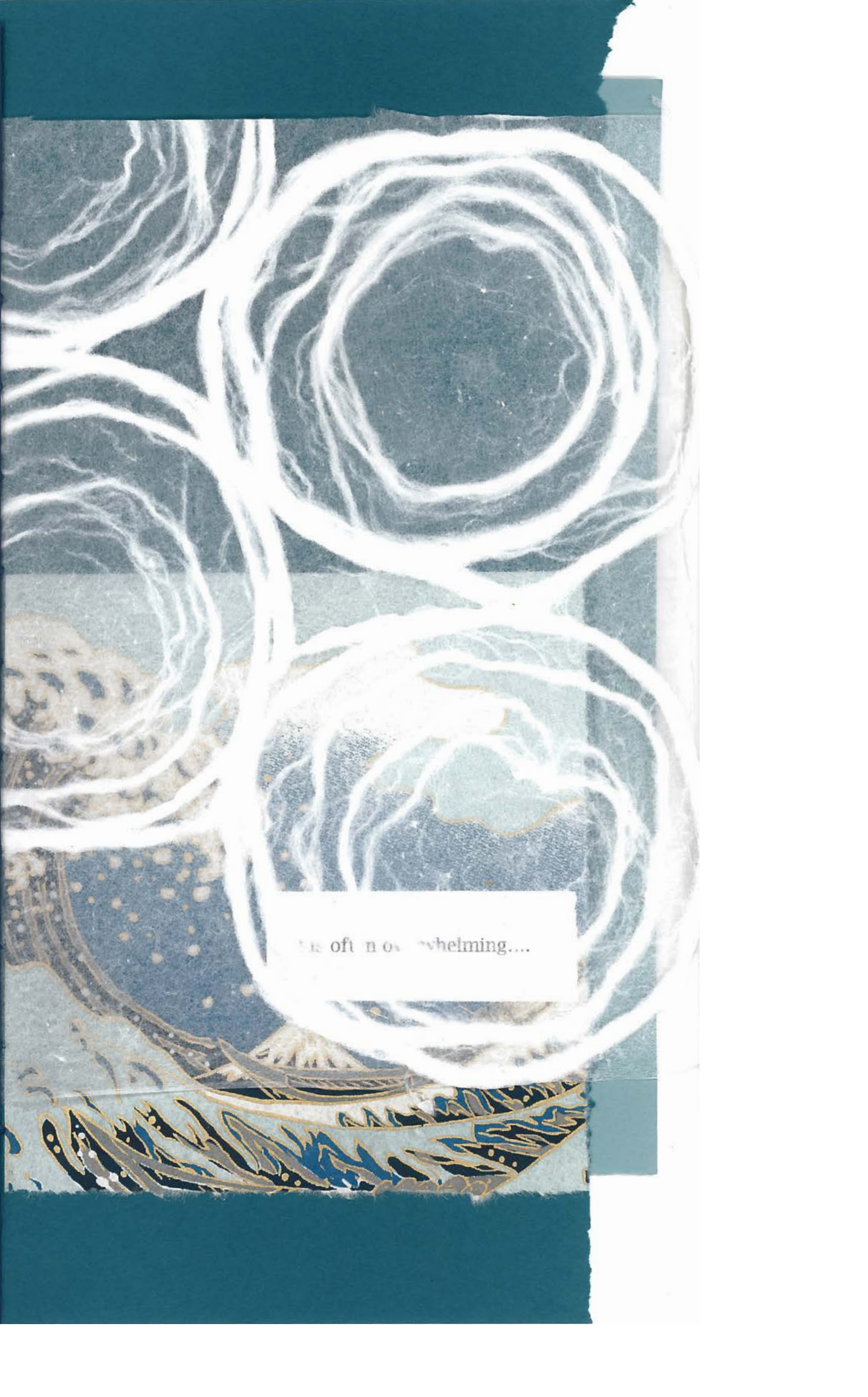
after all,

but a river of guilt, anger, sorrow, and

love.

It just keeps going.





It is often overwhelming....

Grief touches every place, every cell. I will change

It's like existing in another substance

But I will not give up

Now I see grief is not a far distance

After all,


but a moment of intense sorrow

love

It just keeps going



It is often overwhelming....



When all is said and done...

A sense of humor is fundamental to making it through.
On this rugged journey, there is time for lightheartedness.
There's a richness...

because life is revealed in the joy AND the sorrow.
We learn to accept uncertainty.


We don't know how things will unfold either.
We change along with our loved ones.

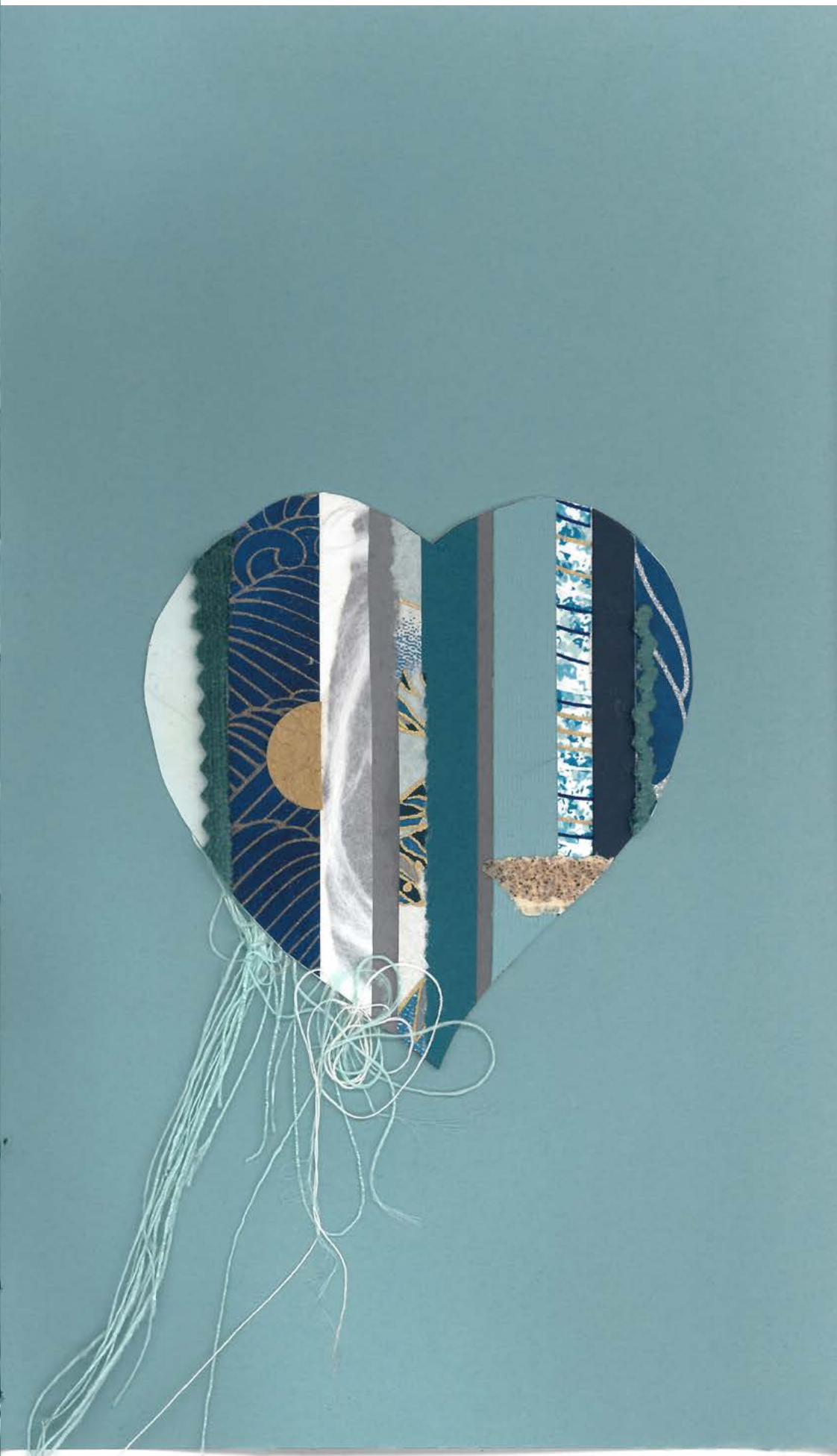
Possibilities exist. The future exists.

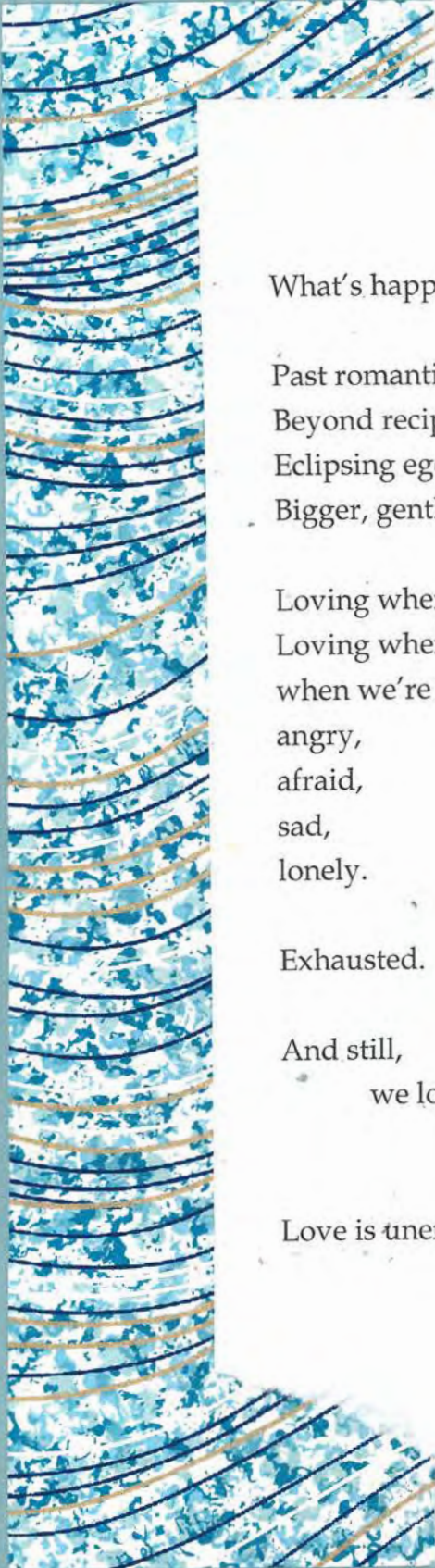
After being a care partner life exists.
We find our way through and start

making meaning of the experience.
It changes how we embrace others.

It changes how we will love in the future.







What's happening is...

Past romantic.

Beyond reciprocity.

Eclipsing ego.

Bigger, gentler...more whole.

Loving when we don't feel very loving.

Loving when we're frustrated,

when we're hurting,

angry,

afraid,

sad,

lonely.

Exhausted.

And still,

we love.

Love is unemptiable.

