

What People
Need to Know
About
Life with Alzheimer's



from 5 brave spirits
experiencing
cognitive impairment

On June 2, 2016, a weekly writing group for people experiencing early stage Alzheimer's and/or other cognitive impairment got together at the Ray Dolby Brain Health Center. The early discussion that day turned to religion. This led to the suggested writing prompt: "What would be your 10 commandments of Alzheimer's?" ...In other words: what do you want people to know about living with this disease?

It resonated.

Here's what we had to say,
from our hearts.

What
we want
you to know
about
living with
Alzheimer's

Keep me in your life.

Interact with me at a level I can relate to:

- Talk softer
- Talk slower
- Don't try to explain things
- Don't overwhelm me with information

I am slower as the day goes by.

Sometimes I need naps.

Hold my hand.

Give me hugs.

When I act weird – I am not doing it on purpose.

I am not consistent.

I mix things up and forget a lot.

I can be inappropriate with my emotions.

Take me out to lunch.

Gentle me.

Don't blame me.

We have a disease.

We are not dying.

And, we are still people.

We can talk. Make jokes. Laugh. Cry.

We will forget, so don't forget about that!

We may act out. We try not to,

but reality can be difficult at times.

We love you. Every one of you.

Even if we don't show it or say it.

You are our fuel. We need you.

Don't baby us. But try to understand.

And, it will all be OK.

please.

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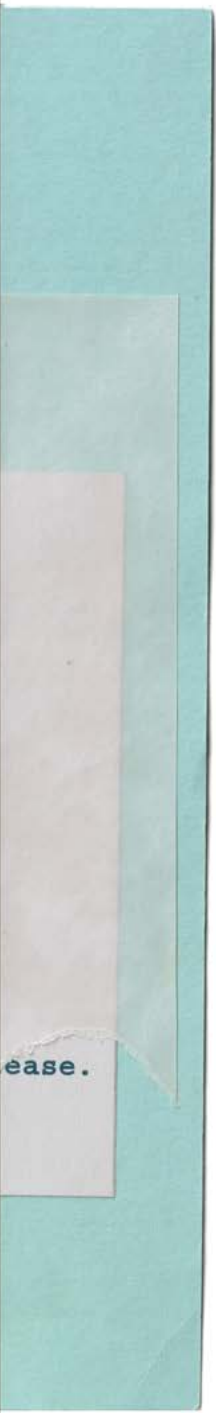
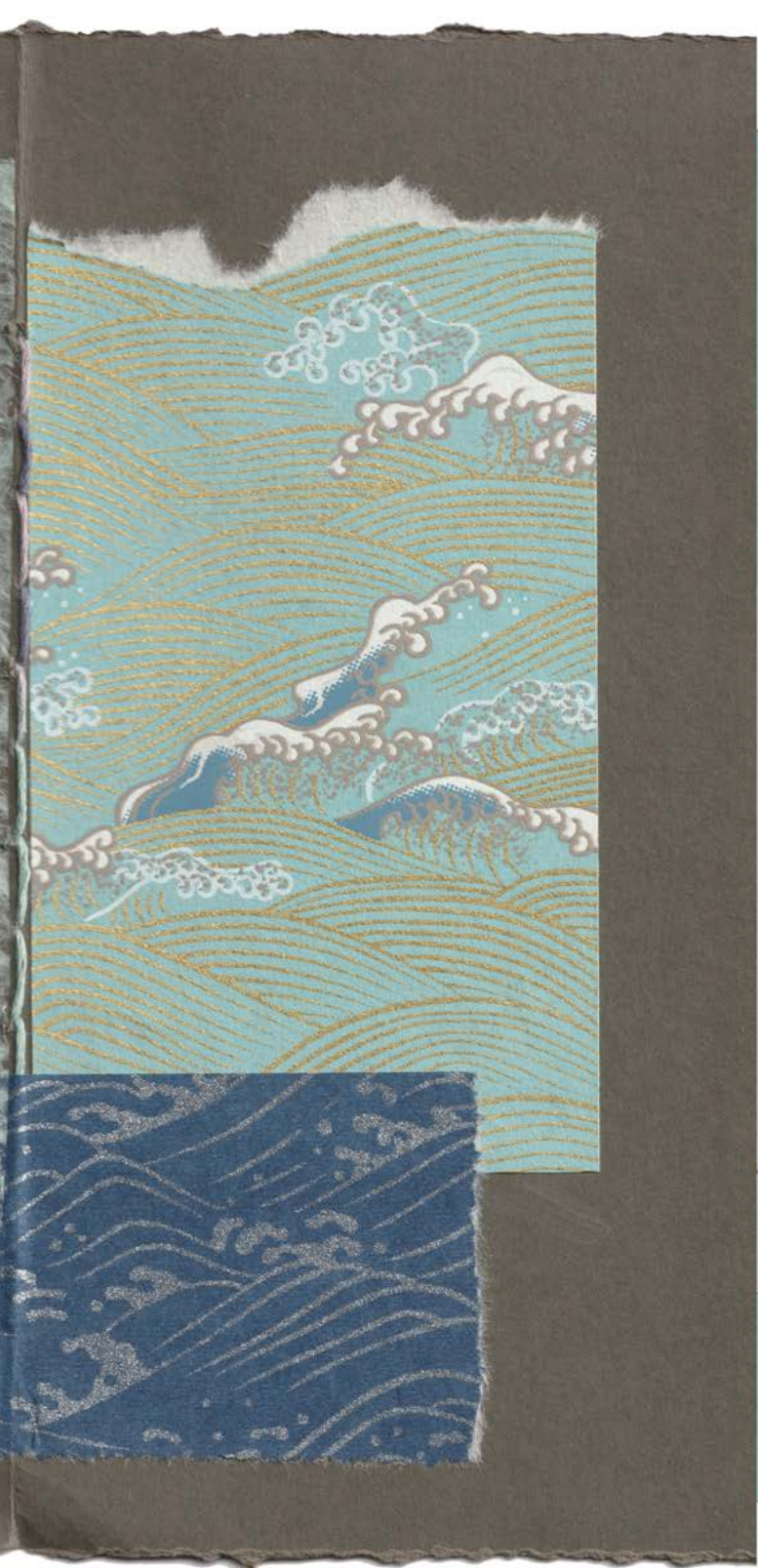
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Change with me.



ease.

From the Alzheimer's United Church

Listen to me.

Sometimes I am lost beyond your understanding.

My brain is unique.

As are those with my physical religion.

Do not feel sorry for me.

I am in a process which may last for many years.

Be patient with me.

Smile with me.

Cry with me.

Laugh with me.

Whoever you are.

Don't tell me I look good.

Do ask how I feel.

Don't tell me I'm slow.

Do give time to just be.

Don't assume that I understand.

Do ask if I have questions.

Don't ignore me.

Do invite me to (almost) anything.

Don't hate me.

Do boss me a tiny amount of love, please.

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Do toss me a tiny amount of love, please.

The 10 Compassions of Alzheimer's

Please don't judge me.

I have a disease that is taking my brain.

There is grace in diminishment if you slow to see it:
slowness is growth too.

I repeat myself; listen again, please.

I miss me too. And, I am still here.

I like to laugh. Share your stories with me... slowly.

Please don't ask me if I remember when we used to.....

Tell the story and my part too. I want to remember it.

I might not remember your name.

It doesn't mean I don't remember you.

Don't be afraid to hug me; a lot. Hold my hand.

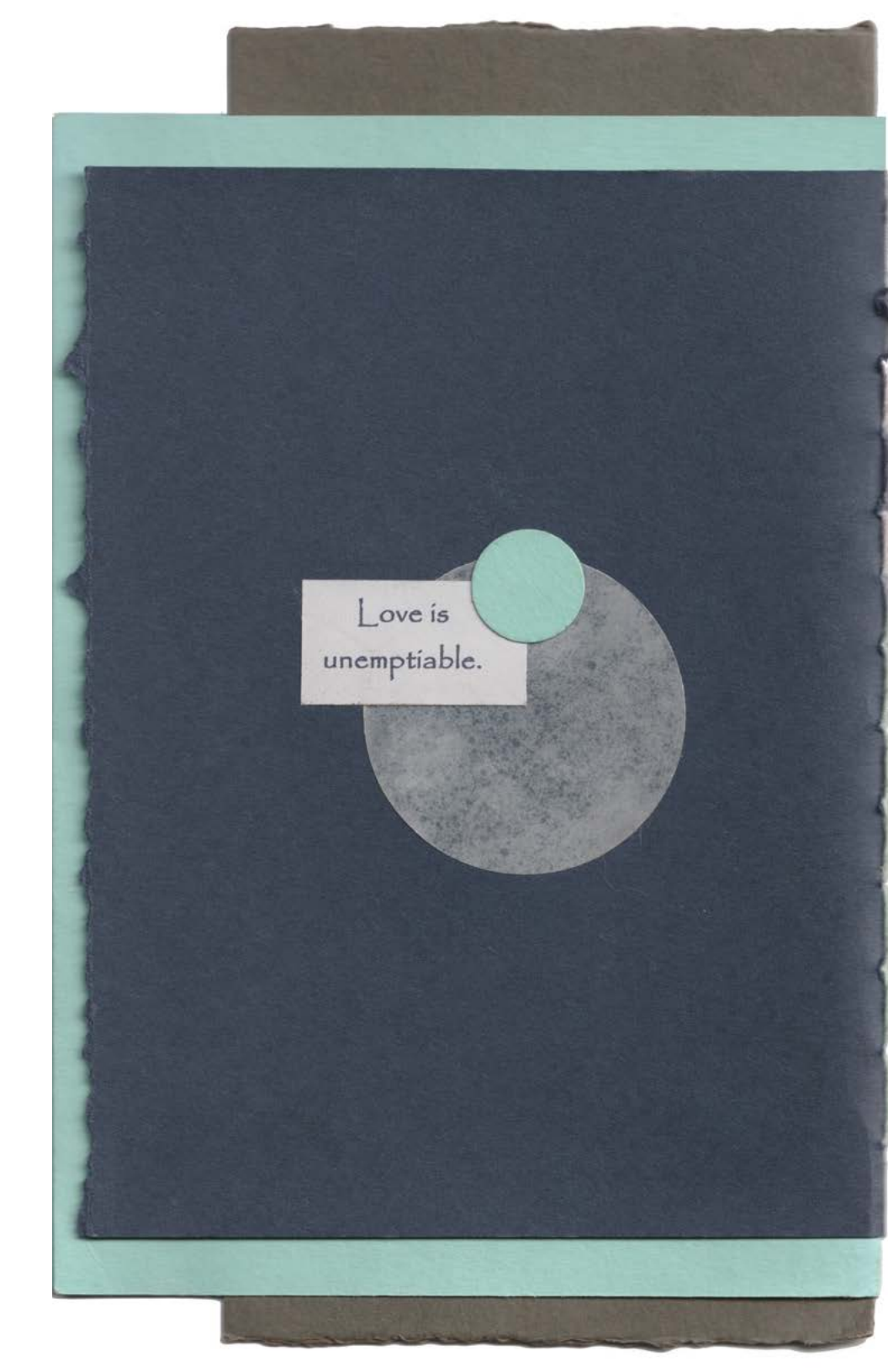
I love connection and touch.

Remember to smile. My life is not the same; and it's not bad.

If I loved you before...I still do.

More than ever. I love and need you.





Love is
unemptiable.