

COPING WITH CHRONIC GRAFT-VERSUS-HOST DISEASE



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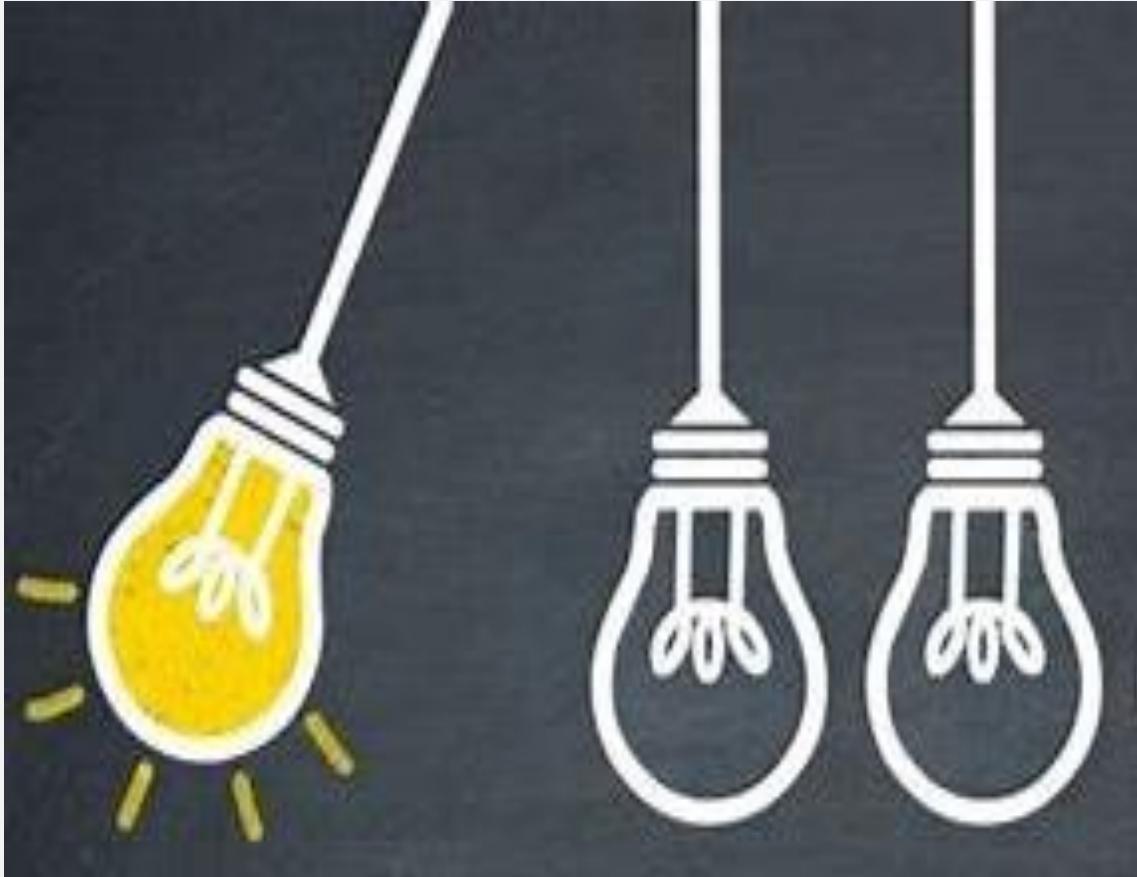
ENHANCING YOUR QUALITY OF
LIFE WHILE LIVING WITH
CHRONIC GRAFT-VERSUS-HOST
DISEASE



Managing chronic GVHD is my full-time job

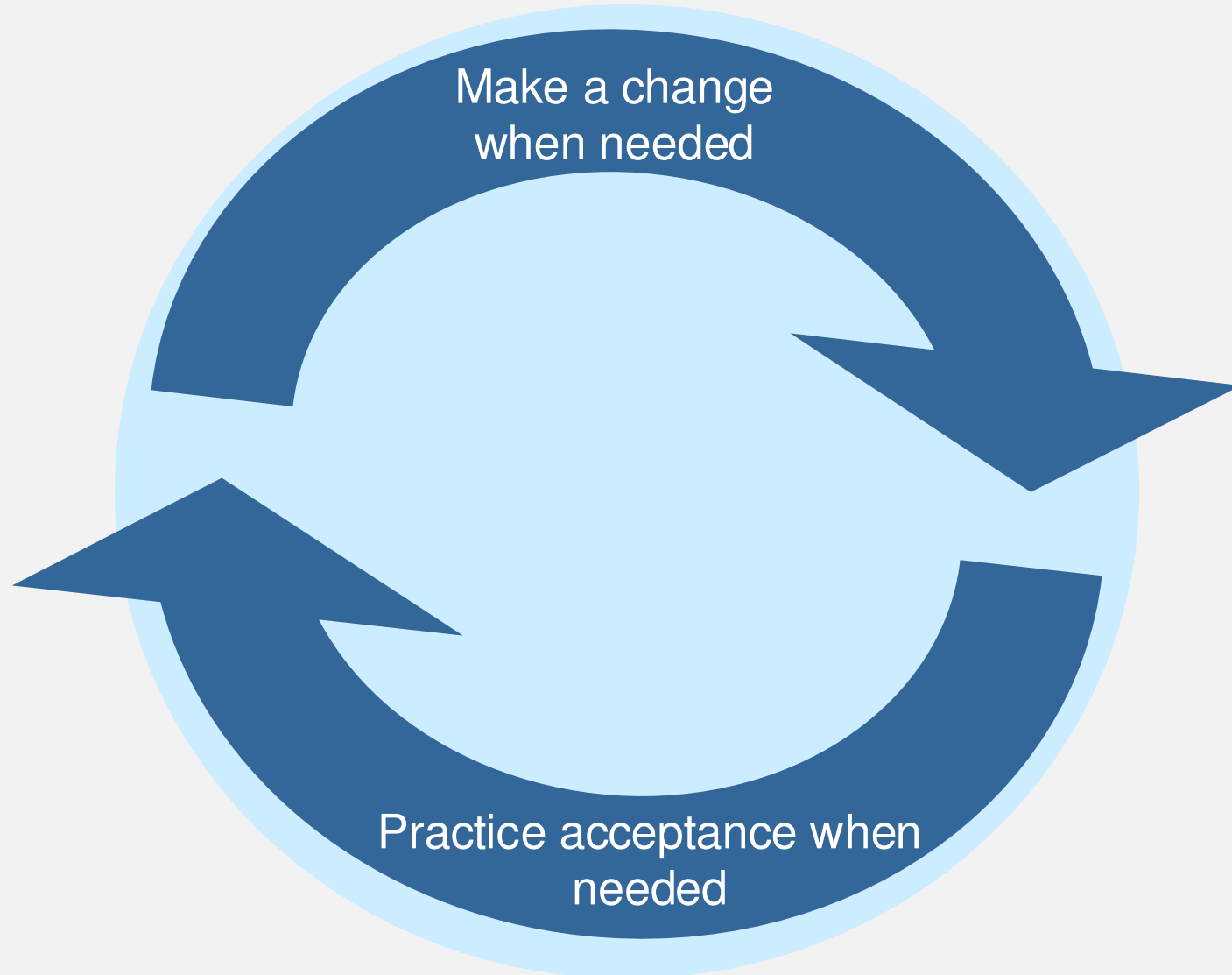
“You can’t stop the medications. So you keep going. Like if you have a job that you didn’t enjoy, but you need an income, so you keep going...this is my job.”

3 KEY POINTS



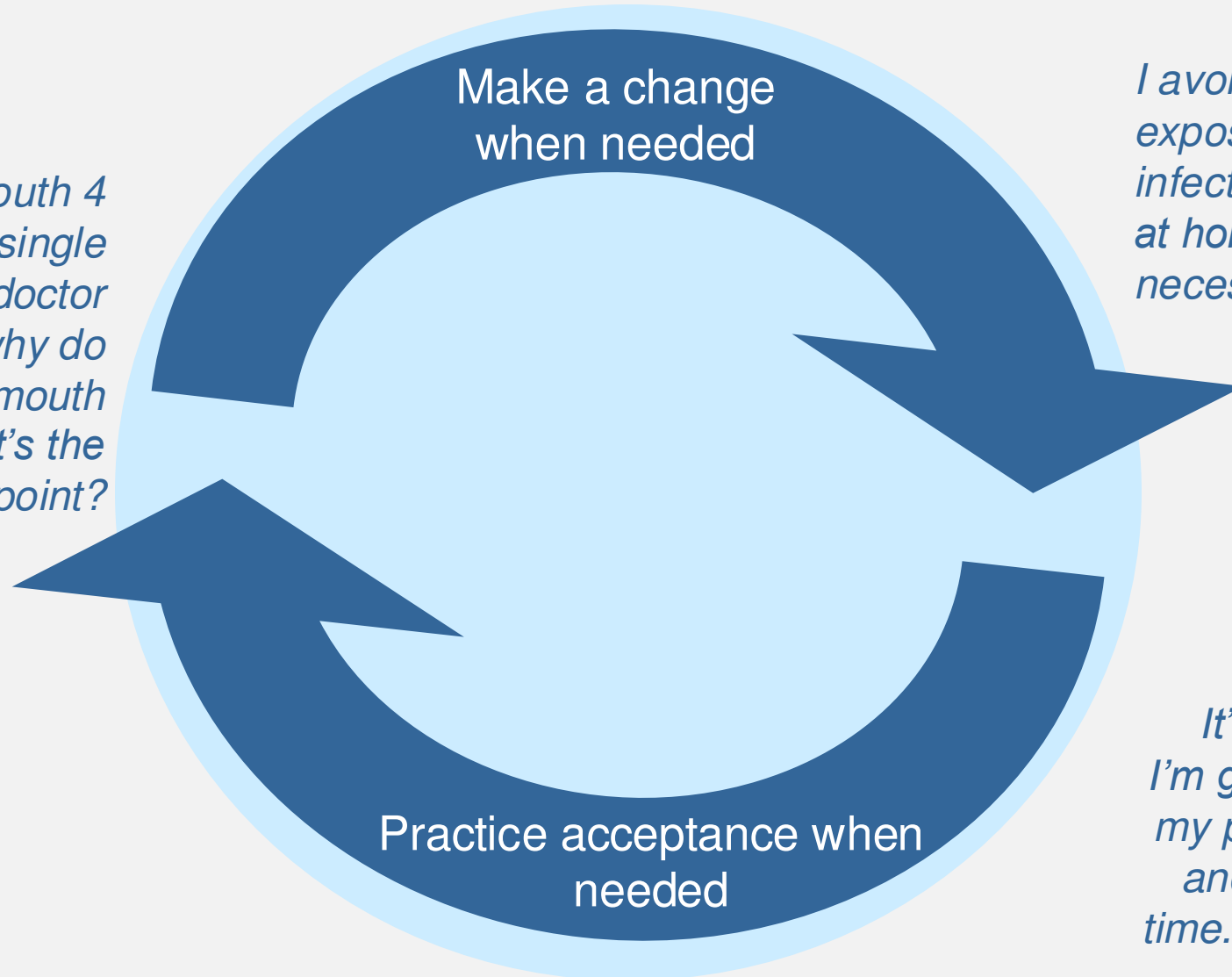
1. Staying informed about your health and asking questions about your concerns is essential to survivorship
2. By using a mindful approach to daily challenges, you can stay present and accepting of “*what is*” while also being more active in deciding “*what comes next*”
3. Each person’s experiences of life after transplant are unique, yet survivors and families can support each other and learn from each other

FINDING *YOUR* BALANCE BETWEEN ACCEPTANCE AND CHANGE



FINDING YOUR BALANCE BETWEEN ACCEPTANCE AND CHANGE

If I am rinsing my mouth 4 times each day, every single day, just like my doctor recommended, then why do I still have some mouth sores and pain? What's the point?



I avoid any place that might expose me to germs and infection. I mostly stay to myself at home. It's tough, but I think it's necessary.

It's hard to figure out when I'm going to be awake to take my pills, do my mouth rinses, and use the skin creams on time. How do I get it all done?

IS IT TIME FOR A CHANGE? (AND CAN I MAKE THIS CHANGE?)

What is one thing that you want more information about or want to take steps to change?

What could get in the way of taking that step?

How can you address whatever is getting in the way of taking that step?

IS IT TIME FOR ACCEPTANCE? (AND CAN I TOLERATE THAT?)



- Whether or not there is more information to get or active steps to take, we still need to sit with uncertainty in day-to-day life
- While you may not be able to control all aspects of your life after transplant, you can manage how much fear and worry 'take the driver's seat'



PRACTICING ACCEPTANCE

- More than one thought or feeling can be true at the same time
- The benefit of acknowledging contradictions is that it allows you to see the bigger picture without sacrificing the real thoughts and feelings that you experience

ADDRESS INTENSE THOUGHTS & EMOTIONS

*"Look what I've
done to my
family"*

guilt,
blame

fear

*"I have no control
over my health
anymore"*

anger

shame

*"Since my
transplant,
everything is wrong"*

What thoughts
are related to
these feelings?



ADDRESS INTENSE THOUGHTS & EMOTIONS



Can I widen my
viewpoint? Can I
get 'unstuck' from
these thoughts?



FINDING COMMUNITY WITH OTHERS WHO ARE MANAGING CHRONIC GVHD

“Even if they didn’t have the same symptoms, they knew the same struggles ... Everyone thinks ‘oh, you’re in remission.’ You know, ‘your cancer’s gone.’ But they don’t understand the things you carry with you like how tired you can get, or your eyes bothering you, or just the other things that go with it.”

“I’m extremely grateful that I got to share things with people that really understand. That’s the best part.”

“I’m going through some decisions about my eye GVHD, and **hearing people talk about their own experiences with that, is helping me like just stay a little calmer.**”

FOR CAREGIVERS:
SUPPORTING A LOVED ONE

Let them tell
you

what they
need



Remain calm

... and don't
rush things



FOR CAREGIVERS: SUPPORTING A LOVED ONE

Expect

*a range of
reactions*



Acknowledge

*that they may
continue to feel
different
emotions*



Remind them

*that there is no
'right' way to
cope with
chronic GVHD*



PEOPLE LIVING WITH CHRONIC GVHD AND
THEIR LOVED ONES AND FAMILY CARE GIVERS:
6 WAYS TO SUPPORT EACH OTHER

- *Acknowledge*
- *Normalize*
- *Validate*
- *Express gratitude*
- *Communicate clearly*
- *Advocate*

THANK YOU



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