



Emotional and Psychological Coping Process of People Living with a Chronic or Rare Disease

Lessons and homeworks...

By Annie Perreault, M. A. Psychologist

Adaptation ou resilience?

Adaptation:

- The ability of a species to survive in a particular ecological setting, to modify to fit a changed environment.

Resilience :

- **Physics:** power or ability to return to the original form or position after being bent, compressed or stretch.
- **Psychology:** ability of a person (or society) to mentally and emotionally cope and move on from a crisis. **It takes time and intentionality.**



A little story...

Once upon a time, there was a person named « Someone ».

This person had to face a diagnosis and cope with a rare disease.

Somone learned with this journey there were steps and phases to go through.

In fact, it was like endless stairs, where Somone could climb or go downstairs without knowing when or where it would end...

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Phases de la maladie

(Fennell, 2012)

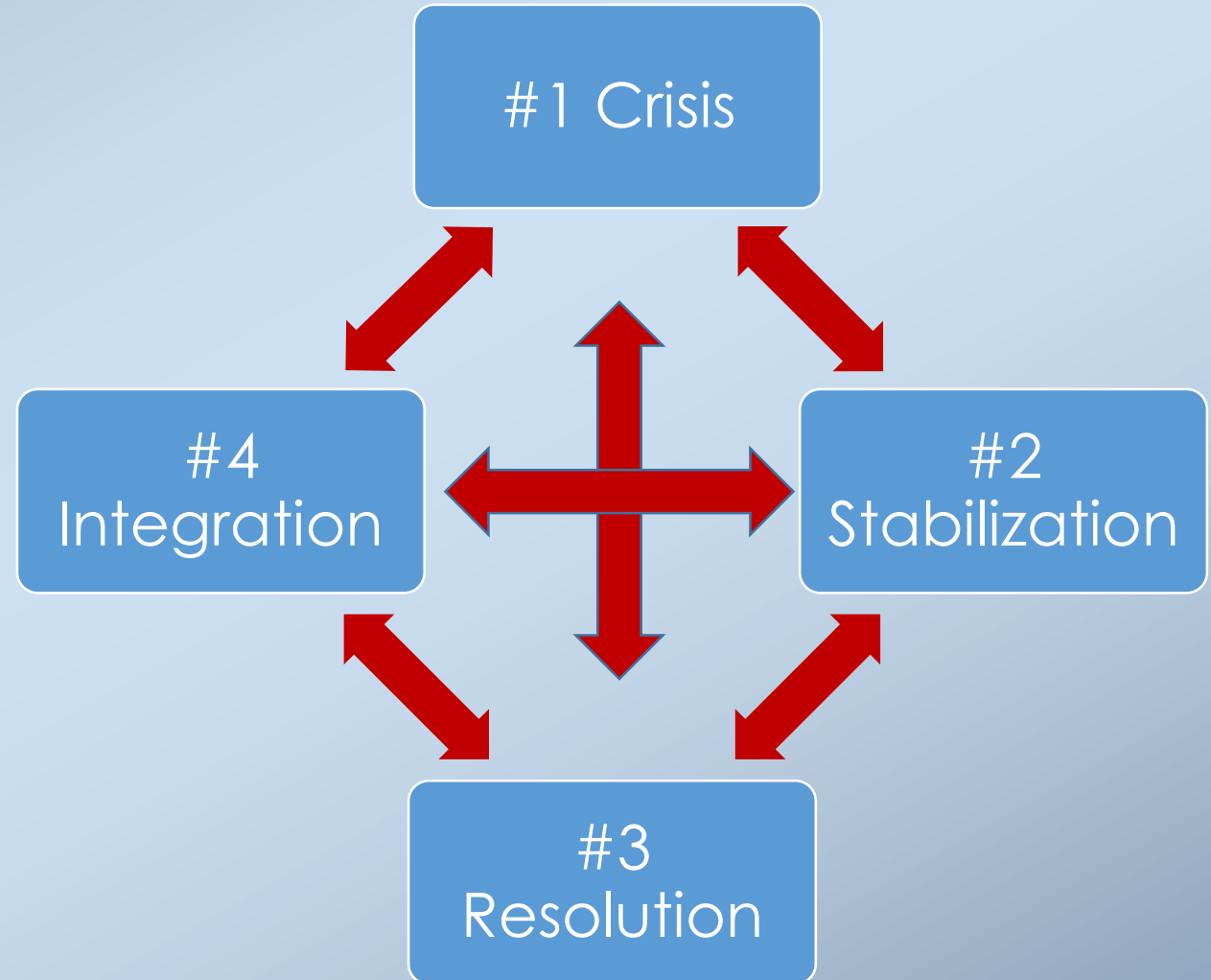
Phase 1 : Crisis :
« **Help!!!** »

Phase 2 : Stabilization:
« **I am coping** »

Phase 3 : Resolution:
« **I am reorganizing** »

Phase 4 : Integration:
« **The new Me** »

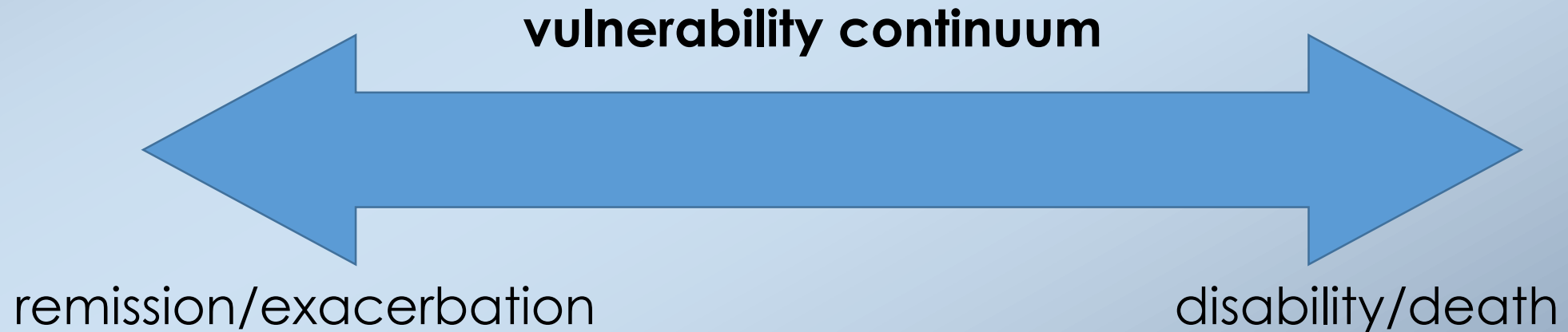
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Three dimensions of the disease

(Donoghue & Siegel, 2000)

- *The social acceptability of the disease*
- *Clarity of diagnosis (ambiguity, diagnostic wandering)*
- *Disease's potential of severity*



Core realities of Chronic Illness (Fennell, 2012)

- Onset (from birth to any other developmental stage)
- Visible or invisible
- Social or familial rejection, cultural stigmatization
- Loss of self and roles changes
- Identity confusion
- No « normal » development
- Disbelief and suspicion
- Clinical induces trauma



Lessons 1 to 7

Leçon #1

Getting support will be your first effort!

- Interactive regulation and self-régulation
- To go through crisis phase, getting support is necessary and lessens isolation.
 - Family, friends, support groups, medical team, etc.

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Lesson #2

Your doctor is not a magician!

- Agenda conflicts
- Mind state
- Informations overload
- Clarity problems

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Lesson #3

Guilt will never be an ally

- Guilt is an expert in camouflage, it often hides other emotions that are useful in the coping process
- Guilt put breaks on the emotional regulation
- Keeps the idea : « **I did something wrong** » to deserve that disease.
- Favorite ingredient of depression

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Lesson #4

Face the shame!

- Shame is an obstacle to a strong SELF ,
- Refers to a SELF that is wrong or broken = inadequacy feeling
- Increase withdrawn and promote depression



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Lesson #5

Get used to uncertainty

- Uncertainty is #1 ingredient in anxiety
- Why do we worry for the worse or something that will probably never happen?

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Lesson #6

Do a reset of you « mind set »

- Trying to pretend as if there is nothing wrong or wishing to go back to the old « me » are big lies !!!
- Face people's comments with « zenitude ».
- Find your « new normal »
- Shop a brand new self image!

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Lesson #7

Recognizing disease phase and being proactive

Adaptation strategies are different in every phase but always with three important points (*physical, psychological and working with others*)

Crisis: *containing the crisis and coping with the trauma, (help of GP and relatives)*

Stabilization: *begin restructuring your life and perceptions, small and humble tasks. (adaptation)*

Resolution: *developping meaning and constructing a new self. A new perception of life and what it can be lived with this illness.*

Integration : *living wisely in the now and attuned. Expanding through your personal, social, professional and spriritual engagements*



Homeworks

Homework # 1

Learnings and discoveries

- Bring out all the positive outcomes from the challenge brought by the disease.
- Find out what were your new abilities and « superpowers » needed to live with this challenge.

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Homework #2

Use your imagination

- Stop for a minute and give your imagination a chance to tell you what would make you feel good or better.
- Put some goals in place that are realistic and with possible positive outcomes.

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Homework #3

Creativity will light up your day!

- Find out a new hobby or an activity that you will use your creativity = excellent for emotional regulation
- No idea? Make a survey!

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Homework #4

Therapeutic Journal

Write about something that bothered you, without judgement. Read it and take a minute to answer to these 3 simple questions :

- 1- I didn't know that...
- 2- I realize that...
- 3- What I need is...

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Homework #5

**Talk, have a chat,
listen, help, give
support, pet an
animal...**

Any positive activity, in
interaction, will be a
source of affective
support et emotionnal
regulation

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Homework# 6

Take care of your body,
mind and soul, in
mindfulness

- Any activity that will have an effect on your body

Move, breath, eat or drink,
laugh, stretch, massage or
touch, swaddle, wash or
bath, rest, sunbath, etc.

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Homework #7

- Take a moment to revisit your day
- Give yourself a moment of gratitude, be thankful to anything that was delightful, even for a little piece of happiness that happened.

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Suggestions

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- Go to www.tccmontreal.com for online ressources.

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