MCI Medical Coaching Institute

Medical Coaching Training Program

Module 1 – Foundation

Contents

Definition of Medical Coaching

Medical Coaching is a process which enables clients to develop emotional, mental and physical resilience in a medical crises and/or challenge.

Let's break it down:

- **"Medical Coaching…"** – the Medical Coaching model is a process-oriented model and not a goal-oriented model. As coaches we facilitate a process that will help the client reach the Life Vision and Medical Coaching goals. When we meet our client for a session, we do not set a desired outcome per session, we meet the client where the client is at the moment and work from that perspective. We work with whatever the client brings into the space, whilst maintaining the alignment to the vision and its goals. **This means:**
  - When the client names what is in the space, we actively explore with the client how we can coach through these issues (medical and other) in a way the brings the client closer to achieving the Medical Coaching goals and fulfilling the Life Vision we named at the beginning of the process.
  - During the session we, as coaches, hold the client's goals and vision and keep bringing the focus back to that vision and those goals.
  - At the end of each session we ask the client what were the learnings and how these learnings serve the goals and the vision.
- **"… enables the client to develop…"** – as we hold the client naturally creative, resourceful and whole we build on what the client already knows and has. We further develop that knowledge to better serve the client's goals and vision. Everything the client needs is already present in the inner system and simply needs rediscovering, updating, upgrading and developing.

  "…emotional, mental and physical resilience…" - In Medical Coaching we work with The American Psychological Association definition of resilience: 'Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats, or even significant sources of stress — such as family and relationship problems, serious health problems, or workplace and financial stressors. It means "bouncing back" from difficult experiences. (https://psychcentral.com/lib/what-is-resilience/)

  Research has shown that resilience is a common human skill. This means that we do not have be extraordinary to be resilient however there are extraordinary circumstances that require that we update and adapt our existing abilities to be resilient.

Resilience involves behaviors, thoughts, and actions that can be learned and developed in anyone.

Factors in Creating Resilience

- The capacity to understand the nature of a situation and process relevant information
- The ability to accept the current reality:
  "I acknowledge things are the way they are at the moment"
- The capacity to make realistic plans and take steps to carry them out
- The ability to ask for help and support
- The ability to separate one's sense of self from the circumstances (I am not what has happened to me)
- A positive view of oneself and confidence in one's strengths and abilities
- The ability to communicate in an authentic and effective way
- The capacity to understand and manage strong emotions and impulses
- The ability to recharge (instead of endure)
- The ability to shift from guilt to responsibility

Developing resilience is a personal journey and it is different from one person to the other.

▸ **"…in a medical crises and/or challenge"** – as Medical Coaches we work with the words our clients choose to define and name what has happened to them, whether they call it an illness, sickness, issue, challenge, curse, fate, event, story etc. We do not judge or evaluate their words according to clinical definitions, we work with their inner subjective language.

The Distinction between Curing & Healing

Curing – is what the medical team and medical system seek to offer. Curing is an evidence-based approach of "fixing" what went wrong in the body and regaining normal function.

Healing – is a process of achieving an experience of health where the illness is not part of the person's sense of self. The illness is something that has happened to the person, resulting in learnings and transformation but it is NOT who the person is.

Healing can be seen as a physical, emotional, metal and spiritual process of returning to an authentic, positive and grounded sense of self and becoming whole (as opposed to feeling fundamentally broken).

In Medical Coaching we focus on the 'Healing' aspect of an illness/medical crisis.The Distinction between Medical Coaching & Counselling.

The Distinction between Medical Coaching and Counseling

The difference is in the focus and direction of movement:

- **In Counselling** one seeks a resolution for a crisis or personal unhappiness. The movement is usually away from something not desired.
- **In Medical Coaching** clients seek to define for themselves what they want, become aware of options and choices, develop appropriate strategies and move towards these outcomes. The movement is forward-looking and goal oriented.

Perspectives on Illnesses and/or Medical Issues

There are 4 common denominators for all medical crises:

1. The field of events is in the client’s body
2. The client lacks choice regarding the characteristics of the crisis
3. The client experiences loss of control over his/her body (the most basic container of the self)
4. The client experiences loss of trust and betrayal of the most fundamental aspects of physical existence

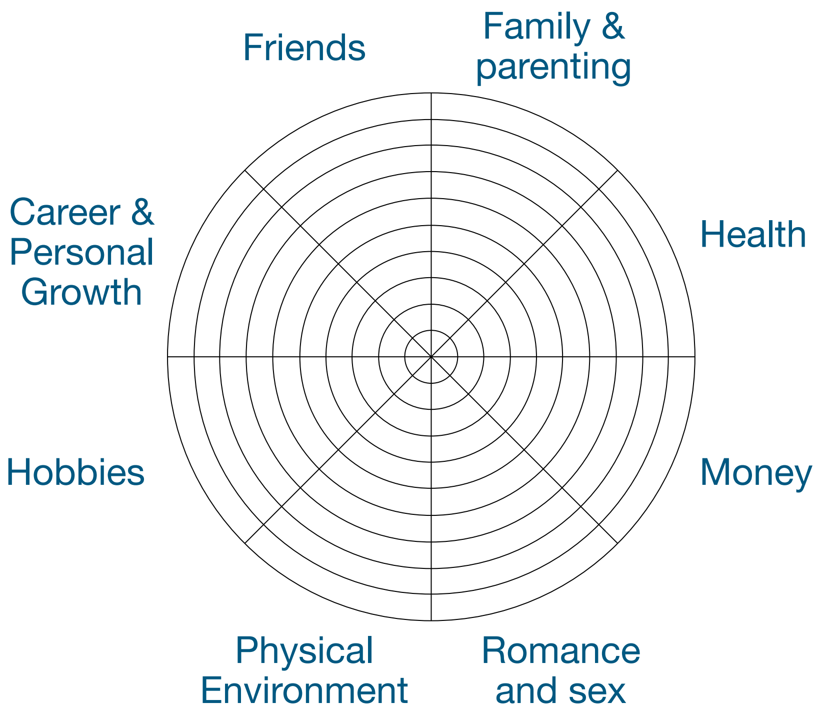
In western culture our body’s health, function, vitality and appearance is associated with self-worth, sexual desirability, social status, financial stability and abundance. A medical crisis and/or chronic illness is perceived to be more than just a physical issue.

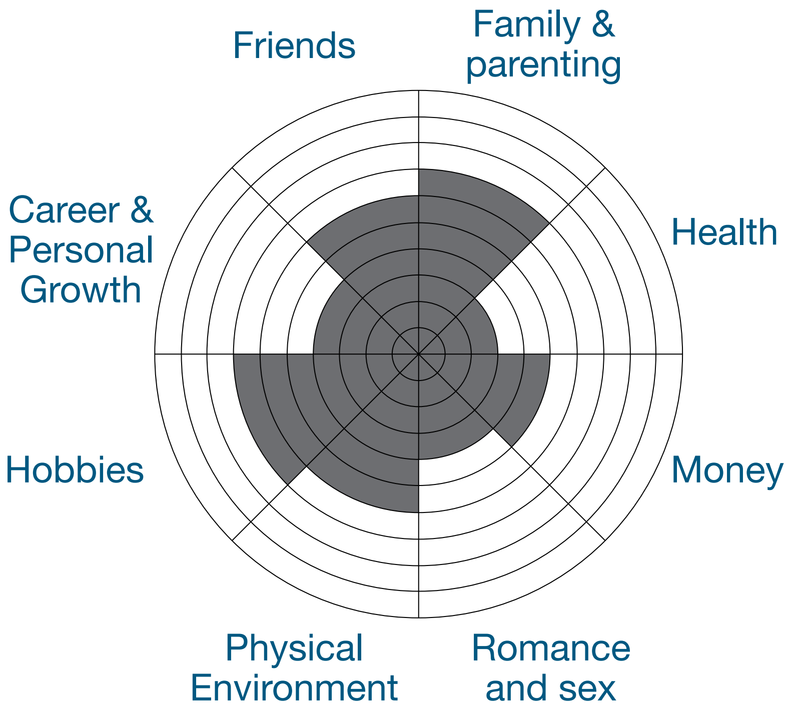
There are many perspectives on illnesses/medical crises.

Our ability to create rapport depends on our ability to understand our client’s model of the world – the cognitive map/internal mental map.

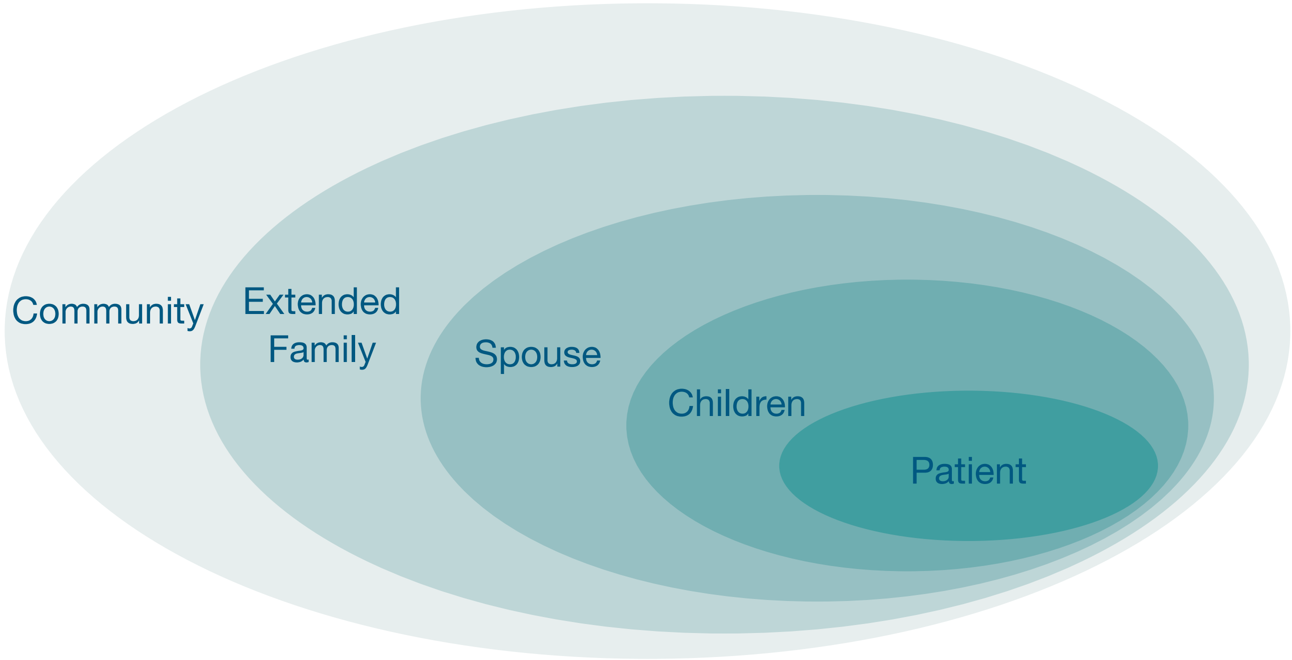
Examples of various perspectives people have regarding illnesses and/or medical issues:

1. An event of dramatic impact on all areas of life





2. An event of dramatic impact on family and community



3. A traumatic event with the potential to create posttraumatic experience

An illness / medical issue can be experienced in a traumatic way.

We might feel shocked by the unexpectedness of it, over whelmed by the dramatic emotions, isolated in the moment, powerless and without a strategy in the face of a force stronger than us.

In order to overcome, we need to make sense of what happened to us, process our emotions and create meaning.

4. An experience of major loss

- Health
- Physical abilities
- Trust in the body
- Autonomy of the body
- Career
- Income
- Friends
- Social Status
- Privacy
- Dreams
- Perception of self
- Self-worth
- Sexuality
- Mobility
- Independence
- Identity

5. A Crisis / Journey of the Soul

Illness shakes the foundation of all that we believe about ourselves and the world.

While we face danger and our own mortality we are also confronted with questions about the meaning of life and the boundaries of our relationships.

There is an opportunity to turn the crisis of the soul into a Soul Journey.

6. “Time Out”

When we find ourselves living a life we did not intend to live, a life that is not aligned with our values and is deaf to our inner calling, the body will call a “Time Out” and offer us the opportunity to rest, rethink and turn our lives in another direction.

7. A Mistake

Biological and/or chemical malfunction of the body.

8. An Experience of Betrayal

Our body is the most primary and basic container of who we are. We learn and experience the world through our body and our senses.

Our relationship with our body is the most important and intimate relationship we will ever have and it is the foundation of all other relationships in our lives.

When our body “turns on us” and betrays our trust, intimacy with ourselves is the first thing we lose. If we cannot trust our body to be safe – how can we trust the world?

If we cannot have intimacy with ourselves – how can we have intimacy with others?

9. Fate / Karma

Fate – A force more powerful than us that shapes and determines our future.

Karma – A circle of action and reaction.
The total of one’s actions – past, present and future, creates a reaction in the form of a new reality.

10. An Inner Imbalance

- Energetic imbalance - imbalanced levels of Chi – life energy
- Emotional imbalance
- Stress

11. Physical Imbalance

- Toxins
- Genetics
- Pollution
- Smoking
- Drugs and alcohol
- Medication and its side affects
- Sleep deprivation
- Extreme exposure to cold and/or warm
- Nutrition

12. A Subculture

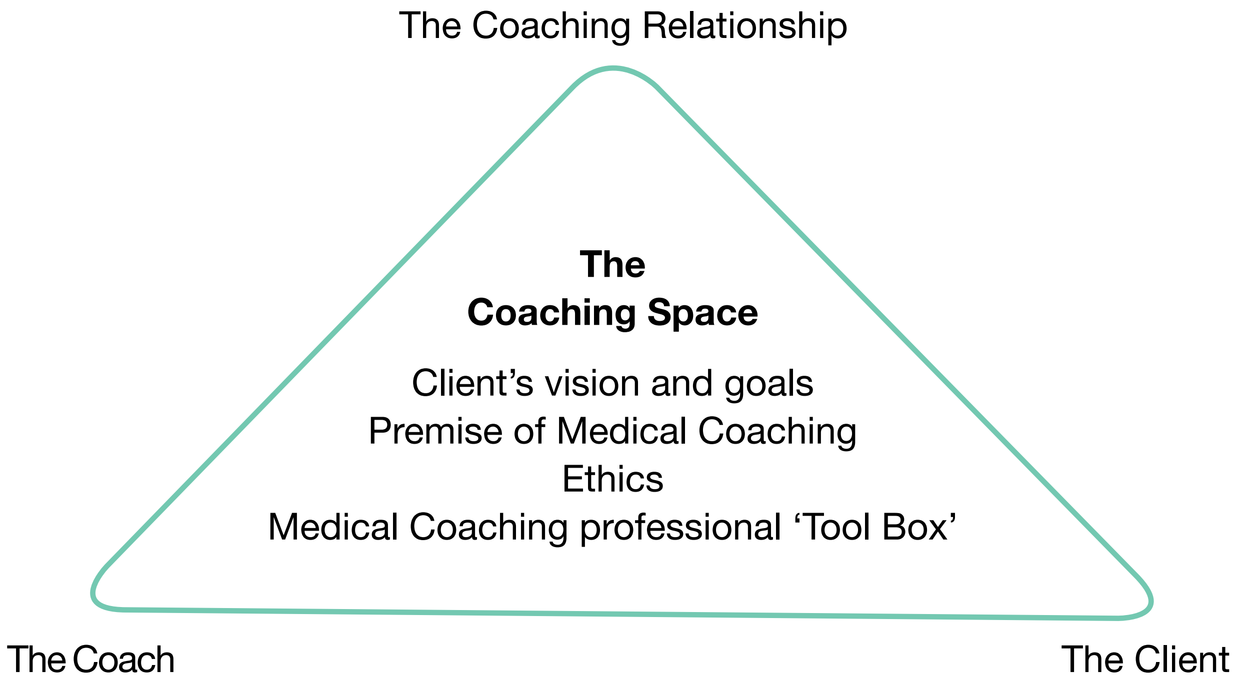
Culture - A group whose members share characteristics, have similar needs, and develop behavioral norms.

Subculture - A subversion to normalcy. A group of like-minded individuals who feel neglected by social standards and come together to create a platform for social criticism and an alternative social and personal narrative.

The premises of Medical Coaching

1. **The Client is naturally creative, resourceful, accountable and whole.**
2. **Every behavior is motivated by a positive intention for the person doing the behavior.**
   a. The present behavior is the best choice with the resources available.
   b. People are not their behaviors.
3. **Medical Coaching addresses the client as a whole.**
4. **A medical issue/illness is a multi-dimensional process: physical, emotional, mental, spiritual, social and environmental.**
5. **Energy flows where attention goes (Law of Attraction).**
6. **There is no failure – only feedback.**
7. **There is no “Objective Reality” only Subjective Narratives.**
   a. People create subjective narratives of the reality they experience.
   b. People are not aware of all their subjective narratives.
   c. People are responsible for their narratives, perspectives and behavior.
   d. People are not their narratives.
8. **People have all the resources they need to achieve their desired outcomes.**
   a. There are no un-resourceful people, only un-resourceful states.
9. **People communicate all the time.**
   a. The most powerful form of communication is non-verbal.
   b. If you do not receive the response you want – change the communication.
   c. Resistance is a request for change.

The Medical Coaching Relationship



The Coaching Relationship

The
Coaching Space

Client’s vision and goals
Premise of Medical Coaching
Ethics
Medical Coaching professional ‘Tool Box’

The Coach

The Client

The Coach

- Is professionally certified in Medical Coaching
- Is knowledgeable in the MCI Code of Ethics
- Has a positive outlook
- Sees the person beyond the illness
- Addresses the client’s entire life
- Calls the client forth into his/her greatness
- “Dances in the Moment” with the client throughout the process
- Has a META-View
- Can create action structures
- Paces and leads
- Is in charge of creating and maintaining rapport
- Calibrates at all times
- Self manages at all times
- Is in charge of creating and maintaining rapport
- Keeps learning and developing professionally
- Receives regular supervision
- Exercises personal maintenance and self-reflection
- Holds the light of hope and focus throughout the process
- Signs a Coaching Agreement with the client

The Client

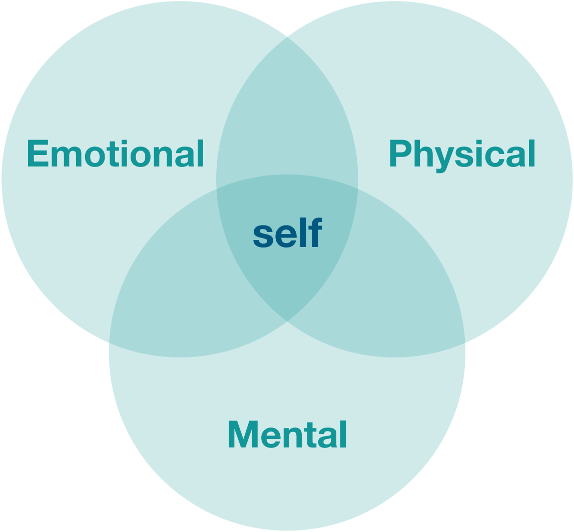
- Is naturally creative, resourceful and whole
- Is accountable
- Holds the agenda
- Experiences him/herself as a person coping with a medical issue
- Is over the age of 17
- Does not suffer from a mental illness
- Does not suffer from clinical depression
- Signs a Coaching Agreement with the coach

The Medical Coaching relationship is:

- A professional coaching relationship
- Designed by coach and client
- Specified in an agreement
- Defined by a professional Code of Ethics
- Dynamic
- Honest
- Brave
- Challenging
- Consistent

Guiding Principles:

1. Medical Coaching addresses the client's sense of self through three dimensions: Physical, Emotional and Mental
2. Sustainable change happens when the process addresses the SELF
3. "Health" is not the absence of illness, it is the state of mind of wholeness
4. "Healing" is the process of becoming whole
5. People heal when they are ready and at their own pace
6. Clients shift when they are ready
7. Different approaches suit different clients at different times. Fit the approach to the client.



The Physical/Geographical Settings of Medical Coaching sessions –

Coach's office:

1. Private space/office

2. Door closed

3. Phone is turned off/muted

4. Coach makes sure there are no distractions or interruptions

Client's house:

1. Private room

2. Door closed

3. Phone is turned off/muted

4. Client makes sure there are no distractions or interruptions

Hospital/ Medical Facility:

1. Private room or space

2. Door closed

3. Phone is turned off/muted

4. Client makes sure there are no distractions or interruptions form family members or friends

5. Client informs medical staff and makes sure to schedule sessions in alignment with the inner schedule in the ward

Online:

1. Private room or space

2. Door closed

3. Phone is turned off/muted

4. Coach and client make sure there are no distractions or interruptions

The Medical Coaching Model

As Medical Coaches we coach our client to create a journey towards an authentic and healthy state of being … a journey back home.

The Four Stages of Medical Coaching

1. Inner Compass
2. Commitment
3. Journey of Health
4. Return Home and Integration

1. The Inner Compass

The Inner Compass is the voice of the client's soul, it is an inner calling that cannot be overheard, overlooked or ignored. It is a call for change, learning, growth and purpose. As Medical Coaches we help our clients turn their inner compass into a clear life vision and set the goals to achieve it.

2. Commitment

Embarking on an inner journey requires leaving the comfort zone, whether the journey is physical or spiritual.

This can be a frightening and challenging thing to do and requires a powerful commitment.

Commitment for change means different things for different people. In terms of commitment to a coaching process we have several tools we can use:

- The Coaching Agreement
- Setting Expectations
- Addressing Payment
- Addressing the Coaching Accountability
- A "commitment scale"

3. Journey of Health

During this journey our clients meet and create allies, discover strengths, cope with fears/challenges/ limiting beliefs, get positive learnings out of past events and tap into their personal and collective sub-conscious.

1. Overcoming hurdles and fear

- Toxic relationships
- Limiting beliefs
- Conflicts
- Anxiety
- Stress
- Loss
- Trauma
- Etc.

2. Connecting with resources and allies

- Empowering relationships
- Empowering beliefs
- Modelling
- Inspiration
- Body – mind connection
- Intuition
- Role models
- Etc.

3. Allowing transformation

In order to create a sustainable process, the client (and especially – the client's brain) needs time to allow assimilation of all the changes – this is called: transformation time.

Transformation takes place when we allow ourselves to receive the positive learning in every situation.

4. Return Home and Integration

The journey of change, much like the "Hero's Journey"*, changes those who choose to embark on it as well as changing the home they return to.

As we complete it is important to address a few points:

- What learnings did the client take from the journey?
- What accomplishments need to be celebrated?
- What challenges remain and how are they different?
- Is there a new calling?

** "Hero's Journey" is a broad category of tales that involve a hero who is called to go on an adventure, faces challenges, wins a victory, and then returns home changed or transformed*

Setting a Life Vision and Medical Coaching Goals

Generally, clients will seek a coach when they identify a desired outcome they wish to achieve. This will usually be a positive, exciting and attractive outcome. An outcome that resonates with their values and makes them feel good as they choose to go on a coaching journey to achieve it.

In Medical Coaching the coaching client comes into the process from several points:

- Wanting to cope/better cope with an existing health/medical crisis
- Wanting to reverse a current process of deterioration in order to prevent a health/medical crisis
- Wanting to manage chronic stress/burnout in order to prevent deterioration that will cause a health/medical crisis.
- Wanting to come to terms and manage an end of life situation.
  (The client can be either the patient, family carers or professional carers)

This means that the clients often enter the coaching space focusing more on what they don't want than what they do want.

Clients come to the first MC session with a **Direction**.
To help the client start articulating the Direction we ask: "Client, what is it that you want?"

Direction

The Direction will include wishes, desires, hopes and dreams.

The Direction is NOT coachable.

As Medical Coaches we explore the Life Vision that the Direction points towards AND we help clients define coachable goals that will help them move towards the Direction which will enable them to be aligned with their vision

As Medical Coaches we meet the client where the client is and we listen to the Direction with empathy AND without judgment.

The next step is to help the client create a **Life Vision** out of the Direction.

Eliciting a Life Vision

The Life Vision is all about the person our client wants to be in this world. It is about achieving fulfillment and purpose.

To create clarity about the vision we need to help clients take a META VIEW perspective and become curious about the possibilities that open for them in terms of purpose and fulfilment when they follow their Direction.
The vision needs to be a statement of 1-3 words about the clients' state of being.

We start eliciting the Life Vision with the following questions:

1. When you achieve (we repeat the content of the Direction) what will your life be like?
2. When your life will be like that, who will you become?

Here are additional powerful coaching questions you can use with your clients to help elicit their Life Vision:

- For the sake of what is it important for you to achieve this (the Direction)?
- When you think about your life, what would you like your overall purpose to be?
- What is your sense of being?
- What will it look like when you have achieved this (the Direction)?
- What will it feel like when you have achieved (the Direction)?
- What does it mean for you to live a fulfilled life?
- If this was your last year to live, how would you like to be remembered?
- If this was your last year to live, what is the word that you would want people to connect to you that would honor/represent you?
- What is important about this (the Direction)?
- Who will you become in the world when you achieve this (the Direction)?
- What will the world receive from you when you achieve this (the Direction)?
- What would you like to give to the world through the way you live your life?

Remember that talking about a Life Vision in the midst of a medical crisis is a radical act of choice.

Setting Medical Coaching Goals

After we have elicited the Life Vision we ask the client to go back to the Direction in order to

start setting goals and establish a coaching plan.

Medical Coaching Goals are coaching goals that have a connection (direct or indirect) to the health/medical issue that the client has brought to the coaching space.

Medical Coaching goals have the same principles as “regular” coaching goals (which you already know how to define with clients).

They need to be:

1. Articulated in a positive language
2. Specific
3. Measurable
4. Timely
5. Pro-active
6. Ethical and legal
7. Aligned with the client’s belief system and values

In the context of Medical Coaching it is important to make sure, together with the client, that the goals are:

1. **Responsible**: taking into account the current medical condition, limitations and restrictions
2. **Realistic**: takes into account the current reality of the client
3. **Resonant**: echoes with what is truly important for the client.

You have 2 coaching tools you can use:

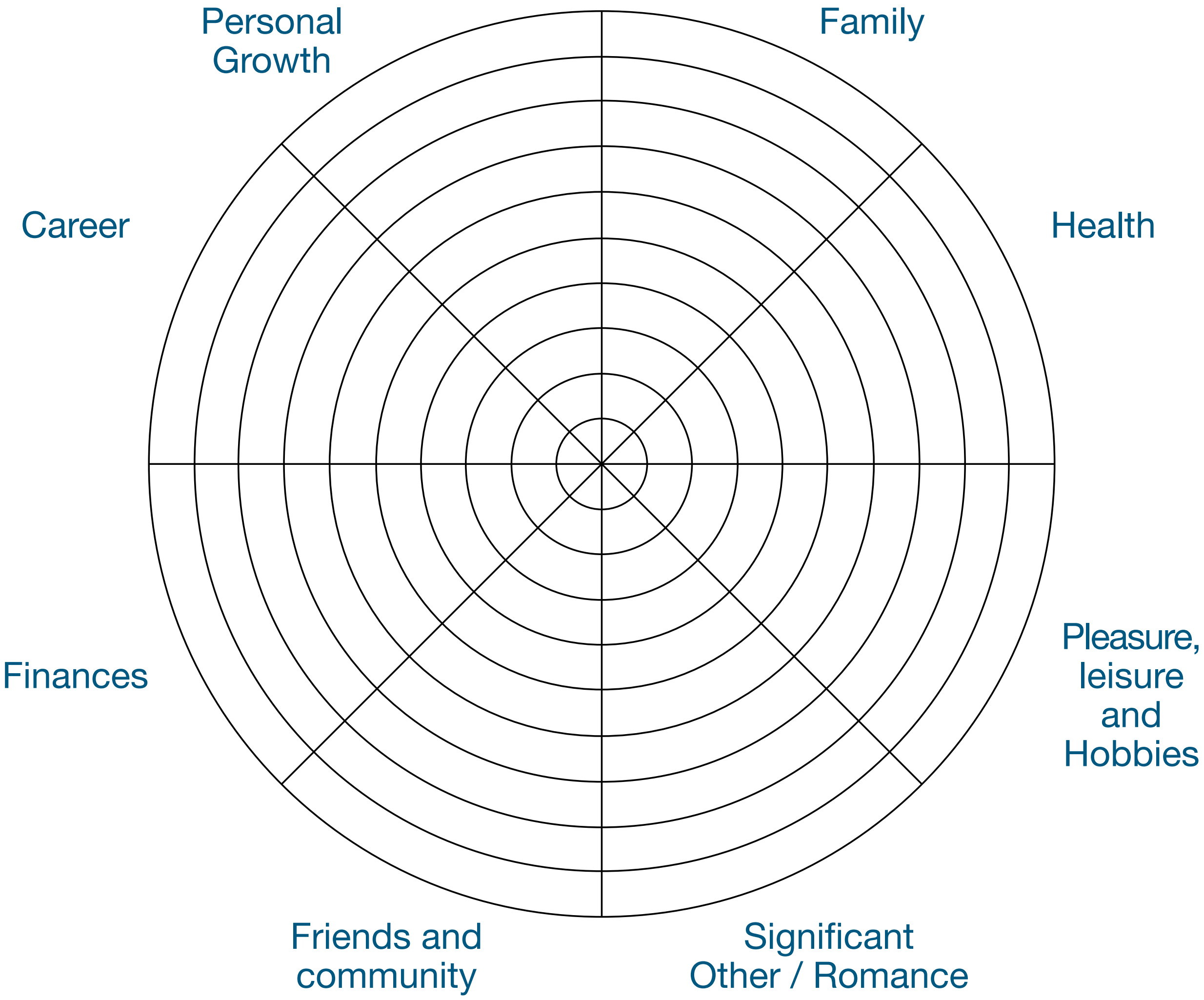
1. **Coaching Wheels.**

   A Coaching Wheel is a visual representation that helps clients rank their level of satisfaction in different areas of life. This representation helps the client and the coach identify where the gaps are between the client's current reality and what the client wants to achieve and to understand the balance or imbalance between the different areas of life.

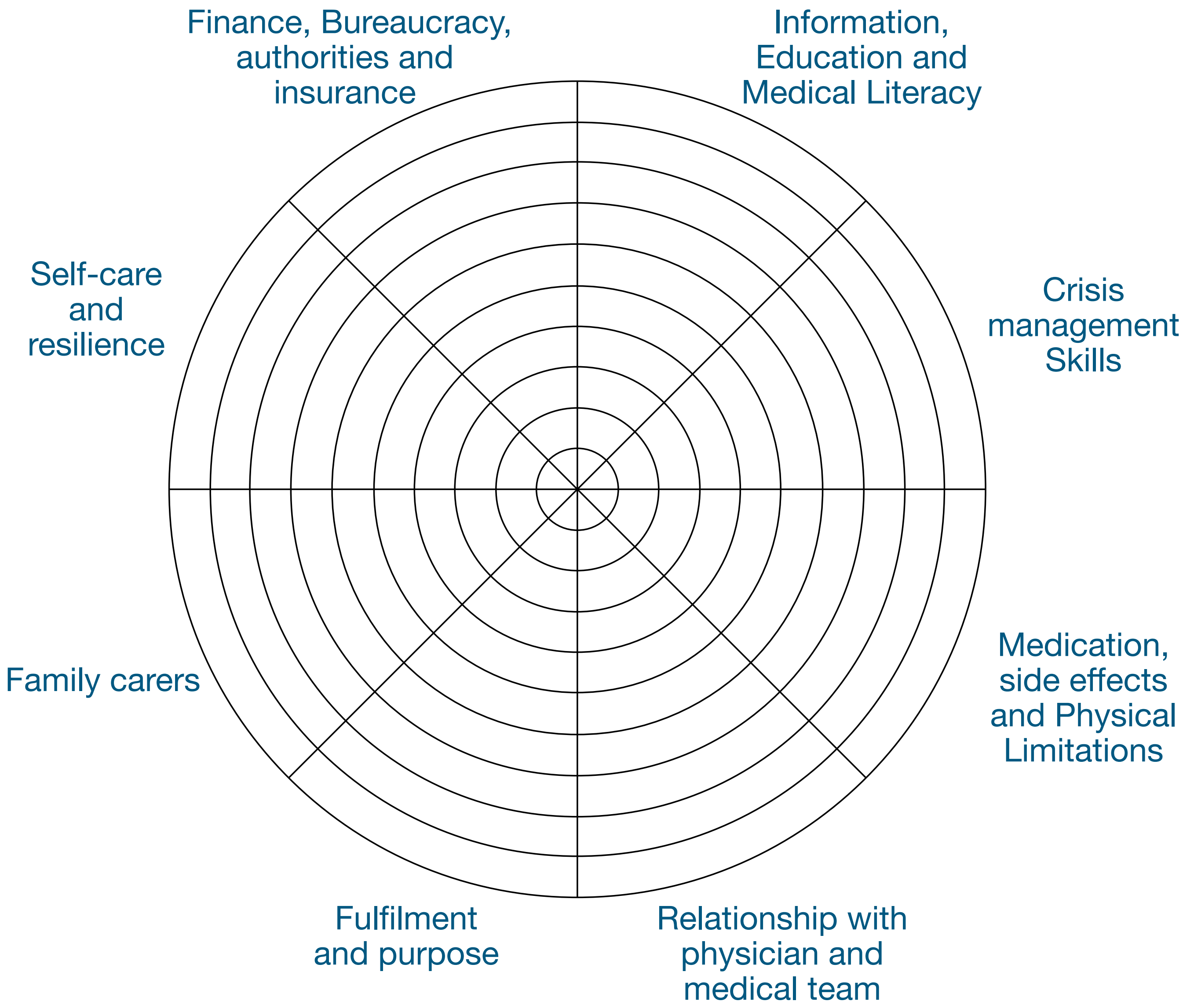
You can use an existing wheel such as the Wheel of Life, Wheel of Illness Management or Wheel of Health or you can use a blank template and ask the client to fill in their relevant life areas.

In the next pages you will temples for: Wheel of Life, Wheel of Illness Management or Wheel of Health and a blank wheel template

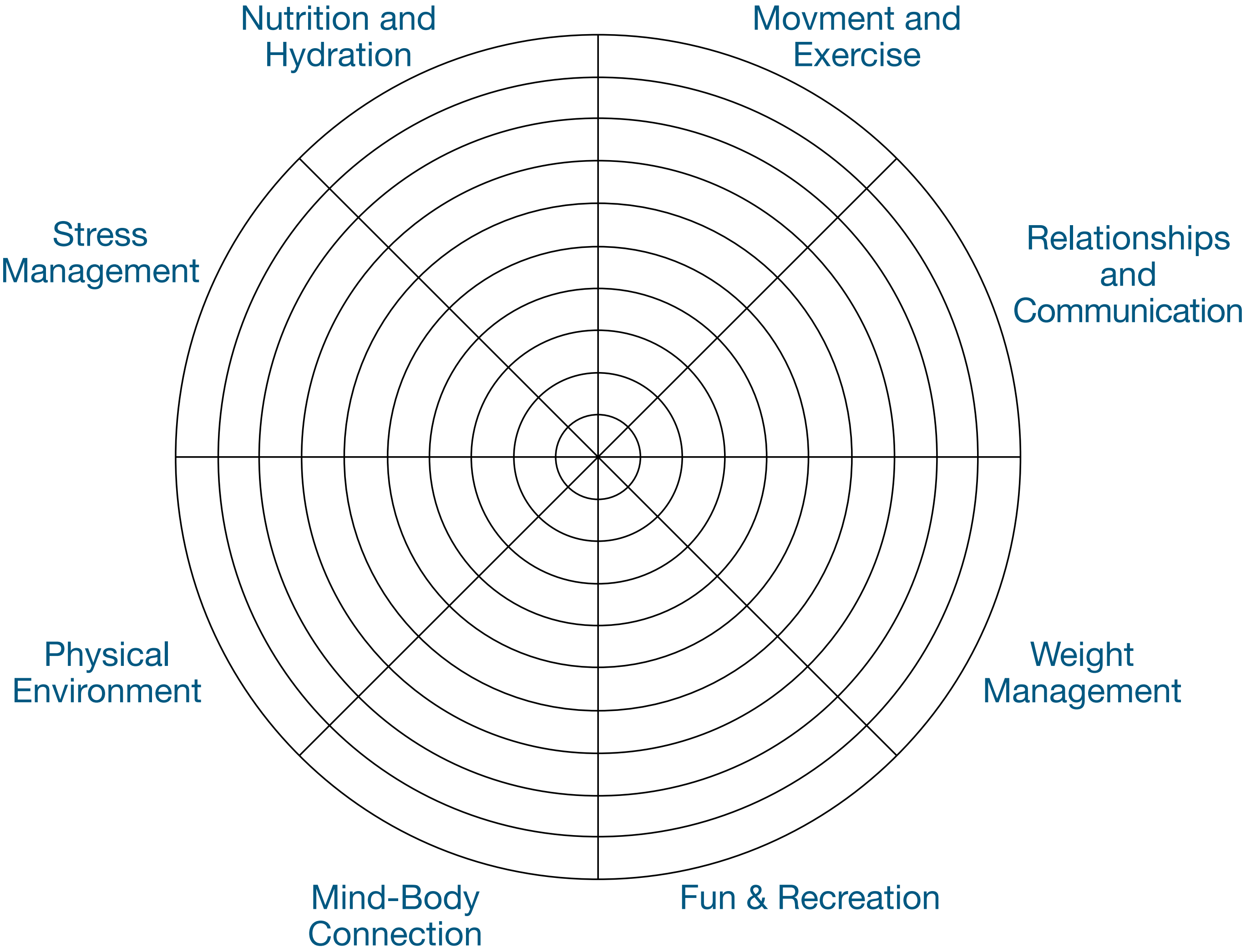
Wheel of Life



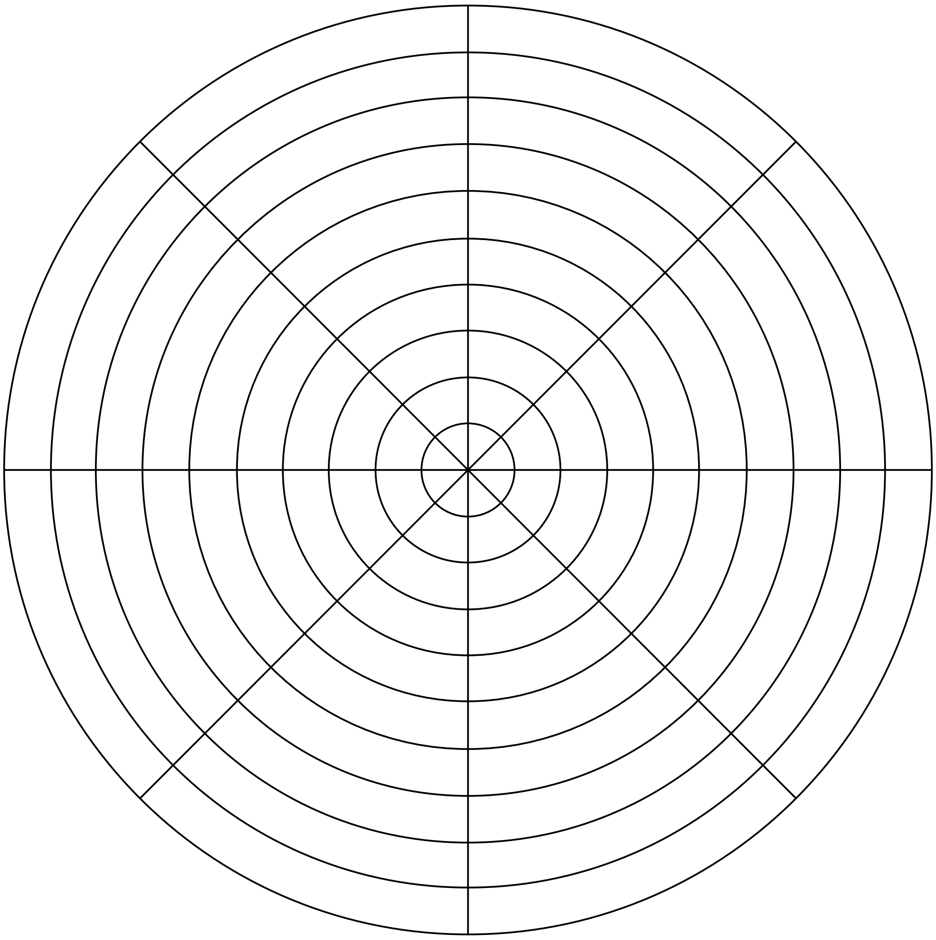
Wheel of Illness Management



Wheel of Health



Empty Wheel template



2. Clarity Circles

- Ask the client to get a piece of paper and pen. Ask the client what areas are currently challenging.
- Ask the client to create a circle for each area and write inside it all the aspects of this area.
- Ask the client to rate the circles according to importance
- Ask the client to choose 1 or 2 circles that will be the focus of the coaching process.

Area/Topic

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Area/Topic

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Area/Topic

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Area/Topic

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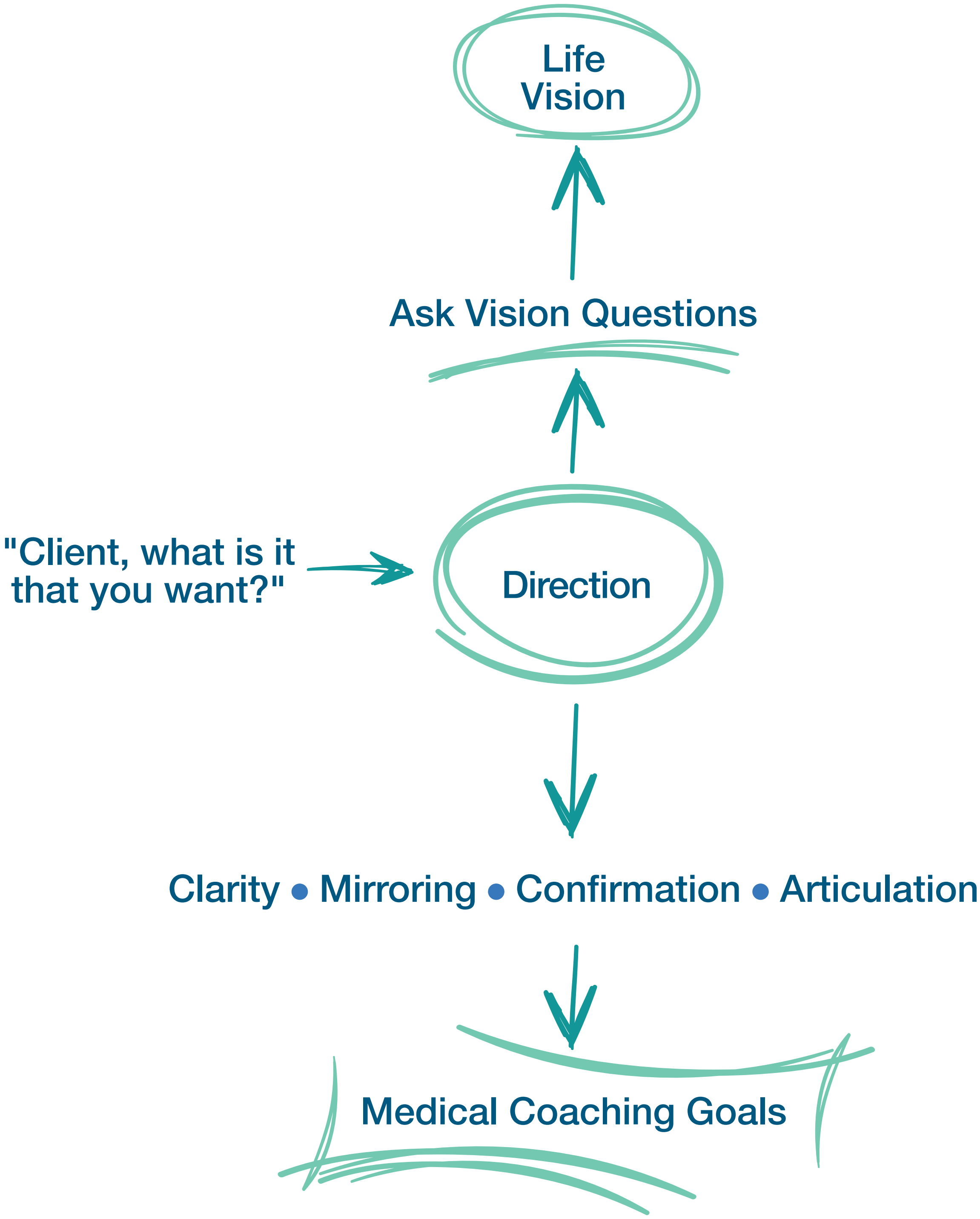
Once we create clarity around the issues that are important for the client, those from which he/she would like to set goals, we do the following:

1. Mirror to the client the issue they spoke of
2. Ask the client to confirm what we have mirrored
3. Set Medical Coaching goals

Summary



Narratives of illness, health, and inner journeys

When a crisis appears in our lives it interrupts the sequence of our life events as we understand, experience and expect them to be. This interruption does not stop our lives, it puts us in a **Liminal Space** where we remain until we are ready to cope, adjust and grow from the changes brought to our life by the crisis. This is true for a medical crisis as well.

Oxford Dictionaries: Liminal - origin late 19th century: from Latin limen, limin- ‘threshold’.

Every time we experience a change or transition in our lives we cross a threshold. Every time we learn something new, we cross a threshold. Every time we choose, we cross a threshold.

These thresholds of waiting and not knowing what “comes next” are everywhere in life and they are inevitable. Each transition over a threshold will interrupt and disorient our lives for a while, regardless of our awareness during the transition.

A Liminal Space is a transitional phase between two well-defined states or periods.

> *…a unique spiritual position where human beings hate to be but where the biblical God is always leading them. It is when you have left the tried and true, but have not yet been able to replace it with anything else. It is when you are finally out of the way. It is when you are between your old comfort zone and any possible new answer.*
>
> *If you are not trained in how to hold anxiety, how to live with ambiguity, how to entrust and wait, you will run… anything to flee this terrible cloud of unknowing.*
>
> - *Richard Rohr (a Franciscan friar ordained to the priesthood in the Roman Catholic Church and an internationally known inspirational speaker).*

We have stepped out of one period/state and have yet to enter or begin another. The old period/state has ended and the new period/state hasn’t begun yet.

We are in between and in neither of the two.

A Liminal Space has the following characteristics:

1. Separation from group of peers
2. Change in social status and position in social hierarchy
3. Changes in self-identity and therefore a sense of disorientation and lack of clarity
4. Waiting…wondering “now what?”
5. A place of transition

During our presence in this Liminal Space a new social structure of a Communitas is formed between all the individuals in this space.

> “*Communitas is a **Latin noun** commonly referring either to an unstructured **community** in which **people** are equal, or to the very spirit of community. It also has special significance as a **loanword** in **cultural anthropology** and the social sciences. Victor Turner, who defined the anthropological usage of communitas, was interested in the interplay between what he called social ‘structure’ and ‘antistructure’; Liminality and Communitas are both components of antistructure.*
>
> *Communitas is an intense community spirit that often refers to the feeling of great **social equality**, solidarity, and togetherness. Communitas is characteristic of people experiencing **liminality together**. This term is used to distinguish the modality of social relationship from an area of common living. From Wikipedia, the free encyclopedia.*”

Examples of Liminal Spaces:

1. **University graduation ceremony**
   The soon to be graduates are physically separated from the rest of the crowd (and at some universities even wear distinct gowns). Throughout the ceremony they are neither students nor graduates - they are in a liminal space. Once they are called to receive the diploma and are declared graduates in front of the crowd they cross a threshold into the status of a university graduate and step out of the Liminal Space.

2. **Engagement.**
   The lovers are not free to pursue other mates or engage romantically with others nor are they officially married to one another.

3. **Cultural rites of passage into adulthood**
   The young boys and girls (in some cultures they are separated according to gender) are separated physically from the rest of the community for a period of time. They are no longer children so they do not enjoy the privileges of childhood nor are they adults yet and so they do not enjoy the privileges of adulthood. Their initiation into adulthood will be the rite of passage – the crossing of the threshold into the status of community adults.

4. **Hospitalization**
   The patients physically leave their home and place in the community and move to the hospital where they will receive treatment and live with other sick people. They are given garments that define their status and they give up all previous social status symbols until they are declared healthy and move back into society.

From an anthropological perspective an illness/medical crisis is a **Liminal Space**.

The ‘healthy’ life has ended and there needs to be a rite of passage so that the person can cross the threshold into a new life with the illness/medical crisis.

Offering our client the perspective that an illness can be perceived as an inner journey, enables them to use the liminality of the illness to heal whatever else (other than the body) needs healing, rebalance the emotions, mourn what has been lost, make room for what is being born and create a rite of passage to cross back the threshold out of the liminal space.

Using myths and stories is a powerful way to connect our client to the “being” of an inner journey perspective.

The Power of Myths and Stories – working with the client's narrative

Myths are cultural stories that form the collective identity of a group. They are created within a context and they are part of the cultural building blocks. The purpose of myths is to design the collective memory and give meaning to daily, unordinary and fantastic/bizarre events. The strength of a myth lays in its ability to emotionally correspond with the human experience on all of its levels and complexity.

We understand the human experience of who we are in this world through stories.

In many ways we are our stories.

Every day is a line, a paragraph or a chapter in the story of our lives.

When an illness/medical crisis appears, it changes the course of our story and some say it integrates itself into the story and becomes an inseparable part of it.

When we shift from our personal story to a wider myth we can give our lives and our illness/crisis a broader and deeper meaning.

Through stories, a person processes the experience of the illness and redefines his/her identity. People learn about themselves by hearing themselves tell the stories of what has happened to them, by seeing how their stories resonate with listeners and through experiencing the way their stories are being retold and shared.

The stories told by people with illness are not stories of an illness, they are stories of the human experience told through an illness, through a wounded body.

For some people, becoming a storyteller is a way of recovering the voice that has been taken or silenced by the illness, its treatments and medical jargon.

These people experience themselves as wounded storytellers trying to survive and support others by making sense and giving meaning to a reality that has become hostile, violent and senseless.

In modern society there is one story/narrative that is acceptable medically, legally and socially – it is the story told by the physician and written in the medical records. This narrative has become the voice against which all other narratives are judged true or false, useful or not.

The wounded storyteller strives to emancipate him/herself from the totality of the clinical story by adding an additional voice to the medical dialogue.

This emancipation is the corner-stone of every healing journey and every Medical Coaching process.

Invisible illness

An Invisible Illness is a chronic condition that is not easily seen and has no obvious external symptoms. Those are Illnesses that can debilitating and prevent a person from performing everyday activities. People with an invisible illness often struggle to explain their condition to others and feel judged or misunderstood. They can look healthy and strong but actually feel sick or in pain.

What Happens to our Story when an Illness enters our Lives?

There are three common denominators to every life story that has been interrupted by an illness/crisis:

1. Loss of control.
2. Invasion – in the case of a chronic illness there is an experience of recurrent invasions (or interruptions) into the intimate space of life.
3. The body becomes something that is separate from whom we feel we are. This impacts the way we experience and relate to ourselves.

Each illness has one clinical story.

Every person has infinite possibilities of how to tell the story of his/her illness. Myths and stories inspire us to tell our own story in a way that can empower us as well as others.

Medical History and Personal Stories

Medical histories are constructed from the outside. They include medical documents, diagnosis, prognosis, test results, pathophysiology, the course of the disease and the potential for various treatments and possible outcomes. They use a standard professional terminology.

These histories address the '**WHAT**' and ignore the '**WHO**'.

Medical histories can dehumanize patients by addressing them as representations of their medical files and not people, e.g. Miriam Green becomes the diabetic in bed 4A. When this happens, we are in danger of losing sight of who she is; we only define Miriam Green by what she is.

The greater the distance a person experiences between who he/she is in the medical records and who he/she experiences him/herself to be - the more anxiety, depression, failure and shame that person is likely to feel regarding the illness and/or the healing.

Western Medicine, which is an evidence-based medicine, tells the story of the medical and physiological evidence and excludes other voices that tell other stories such as: the story of what this illness really means for this person, the story of how the illness has impacted this person's life, the story of how this person sees his/her future, etc.

In the absence of these voices the medical system risks losing its personal touch or even its human touch.

- *Since the 1980's a new approach of medicine has been developing called: Narrative Based Medicine. NBM, a patient-centered approach, addresses the patient as a subject and not an object by taking into account the specific psychological and personal history of the patient in addition to the medical and pathological evidence. For further information, check out articles by Dr. Rita Charon and take a look at the on-line Journal of Narrative Medicine - http://www.theintima.org*

- *Nowadays we can find narrative articles by patients and doctors in leading medical publications such as JAMA and the NEJM*

‘e-patients’

The term ‘**e-patients**’ was coined, by Dr. Tom Ferguson, to describe individuals who are: **equipped**, **enabled**, **empowered** and **engaged** in their health and health care decisions.

The vision of the e-patient movement is one of an equal partnership between e-patients, health professionals and systems that support them.

“Doc Tom” Ferguson (1943-2006) - http://e-patients.net/about-e-patientsnet Pioneering physician, author, and researcher Tom Ferguson studied and wrote about the empowered medical consumer since 1975 and about online health resources for consumers since 1987. In 1993 he organized the world’s first conference devoted to computer systems designed for medical consumers. After attending Reed College, earning a Master’s Degree in creative writing from San Francisco State University, and a medical degree from Yale University School of Medicine, he launched a prolific career in consumer-focused medical writing as the founder of the Medical Self Care magazine. From 1980 to 1996 he authored or co-authored over a dozen books and was section editor for Health, Medicine and Self-Care for the Whole Earth Catalogue. Dr. Ferguson virtually led the movement to advocate informed self-care as the starting point for good health, and to promote a new kind of relationship between knowledgeable medical consumers and medical professionals. His goal was to encourage medical professionals to treat clients as equal partners in achieving better outcomes and change the entrenched practices of the traditional top-down hierarchy of the doctor-patient relationship. With the advent of broad access to the internet, Dr. Ferguson’s long history of advocacy of information-empowered medical consumers positioned him to be a leading proponent of online health information resources. Following his own philosophy, he survived fifteen years with multiple myeloma, far exceeding typical expectations. He relentlessly pursued strategies for both self-care and the newest research and experimental practices for controlling this aggressive cancer. During that time, between relapses and debilitating treatments, he led a migration of medical consumer information to the internet, lectured widely on the emerging field of “health informatics”, and earned a global reputation as a true innovator and pioneer in the field. In 1999 he was one of four to be recognized as an “Online Health Hero”, an award given by the Intel Corporation’s Health Initiative Project. In recent years, he has served as a Senior Research Fellow for Online Health at the Pew Internet and American Life Project in Washington D.C. and a consultant to the Robert Woods Johnson Foundation. He is also an Adjunct Associate Professor of Health Informatics at the University of Texas Health Science

Center in Houston, a Senior Associate at Boston's Center for Clinical Computing, a medical computing think-tank associated with Harvard Medical School and Beth Israel Deaconess Hospital, and most recently joined the University of Arkansas Medical Sciences Center as an adjunct faculty where he initiated a patient centered quality improvement program at the Myeloma Institute for Research and Therapy. Tom Ferguson, M.D. died April 14, 2006 at the UAMS medical center hospital in Little Rock Arkansas, where he was undergoing treatment for multiple myeloma.

Today there are people who say that the 'e' in 'e-patients stands for the following:

'e-patients' are

equipped, enabled, empowered, engaged

+

educated, expressive + expert + electronic

One of the leading agendas of the e-patient movement is 'Participatory Medicine'.

'**Participatory Medicine**' is a model of cooperative health care that seeks to achieve active involvement by patients, professionals, caregivers, and others across the continuum of care on all issues related to an individual's health.

'**Participatory Medicine**' is an ethical approach to medical care that also holds promise to improve outcomes, reduce medical errors, increase patient satisfaction and improve the cost of care. For more information on '**Participatory Medicine**' go to The Society for Participatory Medicine website - http:// participatorymedicine.org/

Today, Dave de Bronkart a.k.a **e-patient Dave** is considered to be a leading voice in the e-patient movement.

After being diagnosed in 2007 with advanced kidney cancer, he rapidly learned to use every aspect of empowerment, technology, and participatory medicine to beat the odds. A founding co-chair of the Society for Participatory Medicine, in 2009 he became an international spokesman for the e-patient movement, and in 2010 left his previous career to work full time in transforming healthcare.

For more information, check out Dave's website - http://www.epatientdave.com/

See additional resources at the 'Resource Library'

Calibration

The ability to identify different “internal states” by looking at the external cues and reading non-verbal signals.

How is it done?
Easy, we pay attention to the other person’s:

- Tone and volume of voice
- Posture (including angle of head)
- Facial color
- Eye accessing cues and pupil dilation
- Muscle tension in the face and forehead
- Movement and balance on the floor or chair
- Breathing pattern

Important note:
Avoid attaching “meanings” to these signals. Calibration is about finding out what each signal or set of signals mean to each unique person.

Rapport

Rapport is the ability to relate to others and interact in a way that creates trust and understanding. It is the ability to see and understand the others’ point of view/model of the world/inner representation, regardless of whether or not you like or agree with them.

Many people describe rapport as a feeling of commonality, being in sync or being on the same wavelength with someone.

The good news is – we can establish Rapport with ANYONE, ANYTIME we choose.

The Theory is:

A. Communication is:
7% words
38% Tonality
55% Physiology

B. When people are like each other, they like each other. Rapport is a process of responsiveness, not necessary “liking”.

The Process is:

A. Subtly Matching & Mirroring non-verbal communication/ body language.

B. Developing a genuine interest in the other person and in the way he/she see and experience the world

There are four levels of non-verbal communication/body language where we Match & Mirror to establish Rapport:

1. Physiology:

- Posture
- Facial Expressions
- Blink rate/pattern
- Lip biting
- Smiling/frowning
- Touching face or lips
- Eyebrow movement
- Body lean
- Head position

2. Breathing rate / patterns / shifts

3. Tone and volume of voice:

- Audio tonal changes during answer
- Time for processing answers
- Pace, speed and tempo

4. Vocabulary:

- Representational system
- Metaphors
- Language or jargon

Rapport and the Heart Energy

An additional aspect of creating Rapport is creating Match & Mirror using the heart's energy. This is Rapport on an energetic and emotional level. This approach is based on the field of Heart Math.

Heart Math "A key area of focus of the Institute of Heart Math Research Center is exploring our emotions and how they affect our physiology, with an emphasis on the physiological effects of positive emotions."

"Heart–Brain Interactions: The heart and brain maintain a continuous two-way dialogue, each influencing the other's functioning. The signals the heart sends to the brain can influence perception, emotional processing and higher cognitive functions. This system and circuitry is viewed by neuro-cardiology researchers as "heart-brain."

"The heart produces by far the body's most powerful rhythmic electromagnetic field, which can be detected several feet away by sensitive instruments. Research shows our heart's field changes distinctly as we experience different emotions. It is registered in people's brains around us and apparently is capable of affecting cells, water and DNA studied in vitro. Growing evidence also suggests energetic interactions involving the heart may underlie intuition and important aspects of human consciousness."

(quoted from the Heart Math web site – www.heartmath.com)

A few important notes on Rapport

1. Make sure you are subtly Matching & Mirroring, or else your client might feel he/she is being mocked
2. Rapport is a two-way street. Avoid creating deep rapport with someone whose emotions you do not feel comfortable with or cannot contain
3. Make sure you come to the session emotionally balanced and can self-manage before you establish rapport. Your client has enough on his/her plate…

Coaching Association & Disassociation

Coaching association and disassociation is different from psychological association and disassociation.

Association – Looking at the experience from within

You feel that you are part of the experience. While in Association you see the experience through your own eyes, hear it with your own ears, and sense it through your body. During the experience you are connected to your emotions, values, and beliefs.

Disassociation – Looking at the experience from the 'Outside' (a Coaching Meta-View)

you feel you are watching, listening to and/or observing the experience from the outside. During the experience you are disconnected from your emotions, values, and beliefs.

The ability to move from an Associative State to a Dis-associative state and vice versa enables the following:

1. Connecting/reconnecting to positive memories and resources
2. Disconnecting from negative emotions or memories
3. Dissolving feelings attached to unwanted thoughts
4. Dissolving emotional triggers
5. Readjusting levels of emotional intensity

Physiology plays a part in recognizing whether our client is in an associative or dissociative state and in helping the client shift from one to the other.

Important Tip:

- To create an associative state – we use language
- To create dissociative state – we use language and physiology

Reframing

In order to give something meaning we need to identify the context or the setting – we need to frame it.

The meaning we give things depends on our point of view/perspective/ internal representation at the time we framed them.

To reframe something is to change its meaning by putting it in a different frame – a different context or setting.

Changing the frame – reframing, helps us change/balance our emotions regarding something, to choose a different perspective, to connect to new resources and to move between associative and dissociative states of mind.

Empathy

Empathy is the ability to accept a person without the need to accept the behavior.

Empathy	Sympathy (Identification)
Empathy is asymmetrical.	Sympathy is to be symmetrically connected with another person in his/her subjective experience.
I see and understand the situation as it reflects in another person's reaction.	I am experiencing what the other experiences, with him/her in the same way.
I can understand another person's subjective experience while remaining emotionally separate from it.	The other's experience becomes mine and I am focused on my emotions and myself.

Empathetic Listening – listening with an open mind, without defense, judgment, objection or identification.

Coaching Curiosity

Coaching Curiosity is different than ‘everyday’ curiosity.

As coaches we use curiosity as a professional skill to help the client explore beliefs, perspectives, behaviors, options and possibilities outside the comfort zone.

To access this skill, we need to be to do the following:

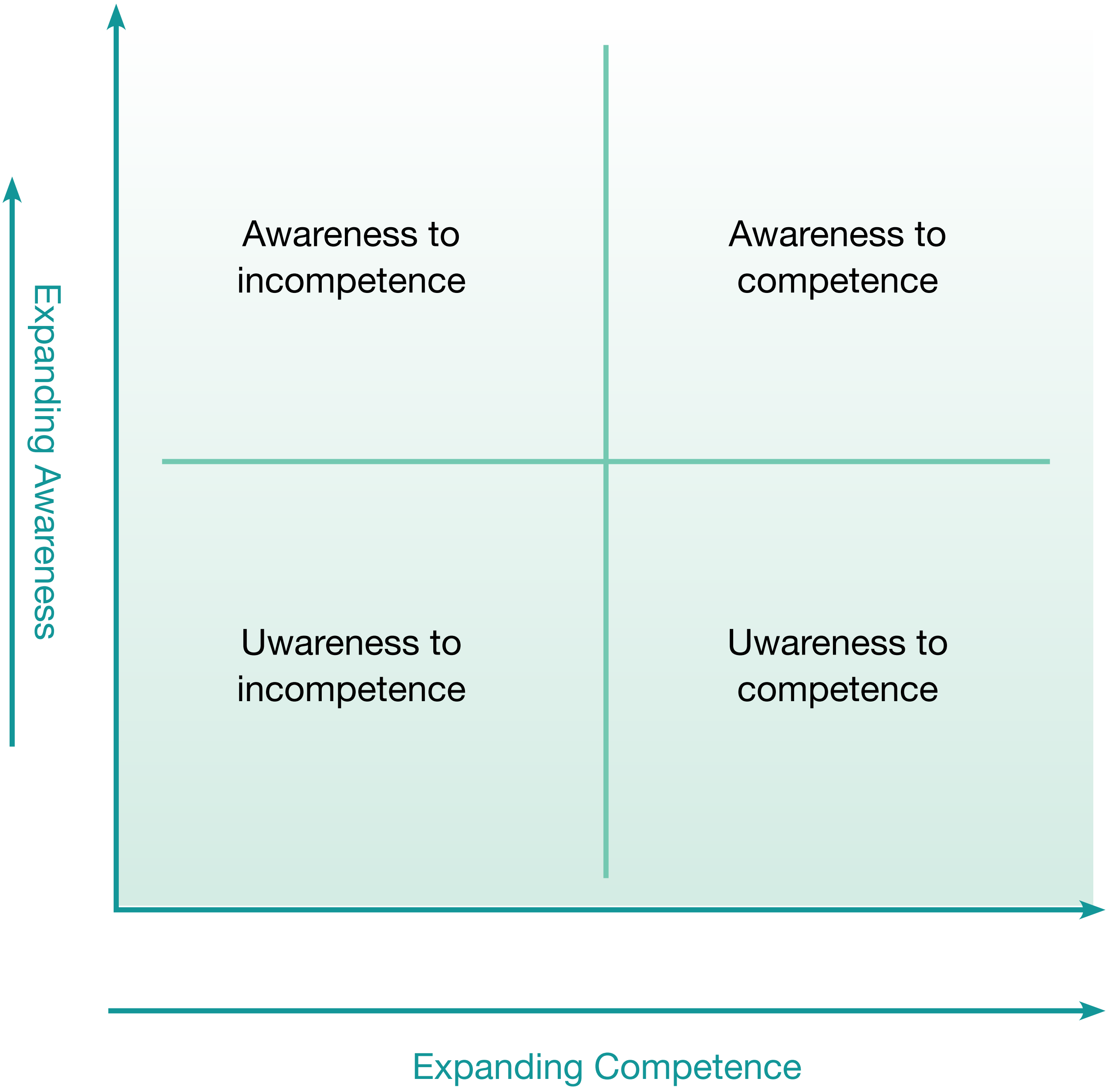
1. Release our own beliefs, perspectives and judgment
2. Release any need to ‘save’ the client
3. Be empathically unattached to the content and emotions the client brings to the coaching space
4. Be curious about the client’s experience and not the “juicy details”

Examples for Coaching Curiosity questions:

- What can become possible?
- What else?
- For the sake of what?
- How does that feel in the body?
- What are you not saying?
- What might be another way…?

Raising Awareness

Our job as coaches is to help our clients shift in two directions:
From unawareness to awareness
and from incompetence to competence.



Coaching clients through Emotions

Some of these emotions arouse us and some calm us down. Some are pleasant and some are unpleasant.

- Anger
- Shame
- Fear
- Sadness
- Happiness
- Surprise
- Interest / curiosity
- Disgust

Important to remember:

- Our emotions help us survive in the world
- We have more unpleasant emotions that pleasant ones
- When we allow ourselves "to be" with them and express them with attachment they become less unpleasant

All the rest of our emotions arise from the eight basic emotions.

Loneliness – can arise from sadness

Frustration – can arise from anger

Self-consciousness – can arise from shame

Suspiciousness – can arise from fear

The connection to the basic emotion is subjective and derives from the person's beliefs.

Emotions can get messy

1. Sometimes we fake emotion to get what we want
2. Sometimes we cover our real emotions with other emotions, e.g. we react in anger when we actually feel sad
3. Sometimes our real emotions are so messed up that they get us into trouble, e.g. if I have experienced a lot of fear as a child, I might grow up to be an adult that needs to feel safe, loved and accepted. I might choose to behave in an over-protective way and end up driving people away from me

When we welcome our emotions and listen to them instead of trying to cover them up and silence them, they become more manageable.

We function better when we are aware of our basic emotions.

These help us acknowledge what we need from ourselves and others and help us accept who we really are.

Emotions are an inseparable part of an illness and they "show up" regularly in the coaching room as well. There is no way around them – only through them, which means – we need to deal with them!

In order to deal with the emotions our clients bring into the coaching space in a way that will empower our clients AND contribute to the success of the coaching process, we need to remember the following:

4. Every illness expresses itself emotionally as well as physically
5. The emotions are a normal reaction to an abnormal situation
6. Not everyone has an 'emotional vocabulary'.
   The more the client can articulate the emotions the more he/she can manage them
7. People are not their emotions
8. People define emotions in different and subjective ways
9. Emotions are not sensations
10. There are no "good/positive" or "bad/negative" emotions only "balanced" and "imbalanced" emotions.

Balanced	Imbalanced
Happiness	Euphoria
Anger	Rage
Fear	Anxiety
Confusion	Disorientation
Sadness	Despair

In Medical Coaching we aim to enable our clients to balance the imbalanced emotions and learn how to "be" with them, in order to collect deep learnings and identify resources.

Holding the Space

Holding Space is not something exclusive to coaches, facilitators, therapists or palliative care nurses. It is something we can all do for each other – for our partners, children, friends, neighbors, colleagues, clients and even strangers.

In coaching we tend to look at Holding Space for clients as an intuitive state of being that comes naturally as we complete our basic training. Unfortunately, that is not the case for everyone. Holding Space is a complex practice that evolves as we practice it, and it is unique to each coach, each client and each situation.

In Medical Coaching Holding Space is a professional skill.

These 15 steps will help you master this skill:

1. Create rapport.
2. Be actively empathic and not sympathetic.
3. Give your client time to process. People move when they are ready.
4. Be willing to walk alongside your client and not lead.
5. Allow your client to be vulnerable, weak and safely express emotions.
6. Give your client permission to trust his/her own intuition and wisdom.
7. Allow the client to make different decisions from those you would.
8. Keep your ego out of it.
9. Don't judge.
10. Don't try to fix.
11. Be unattached to the process and the results.
12. Be ok with the 'not knowing'.
13. Focus on the client's experience and not the story.
14. When working with carers – remember you are holding the space for a client that is actively holding space for others.

Last, but not least –

15. Make sure you have someone to hold the space for you.

Resource Library:

Personal Narratives –

1. **Choices that can Change your Life**, Caroline Myss
   TEDxFindhornSalon - https://www.youtube.com/watch?v=-KysuBl2m_w
2. **The art of being yourself**, Caroline McHugh
   TEDxMiltonKeynesWomen - https://www.youtube.com/watch?v=veEQQ-N9xWU
3. **The two kinds of stories we tell about ourselves**, Emily Esfahani Smith - https://ideas.ted.com/the-two-kinds-of-stories-we-tell-about-ourselves/?utm_campaign=social&utm_medium=referral&utm_source=facebook.com&utm_content=ideas-blog&utm_term=humanities
4. **The Spoon Theory** by Christine Miserandino www.butyoudontlooksick.com

My best friend and I were in the diner, talking. As usual, it was very late and we were eating French fries with gravy. Like normal girls our age, we spent a lot of time in the diner while in college, and most of the time we spent talking about boys, music or trivial things, that seemed very important at the time. We never got serious about anything in particular and spent most of our time laughing.

As I went to take some of my medicine with a snack as I usually did, she watched me with an awkward kind of stare, instead of continuing the conversation. She then asked me out of the blue what it felt like to have Lupus and be sick. I was shocked not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. She had seen me cry in pain, what else was there to know?

I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I was a little surprised as being my roommate in college and friend for years; I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what it felt like, not physically, but what it felt like to be me, to be sick.

As I tried to gain my composure, I glanced around the table for help or guidance, or at least stall for time to think. I was trying to find the right words. How do I answer a question I never was able to answer for myself? How do I explain every detail of every day being effected, and give the emotions a sick person goes through with clarity. I could have given up, cracked a joke like I usually do, and changed the subject, but I remember thinking if I don’t try to explain this, how could I ever expect her to understand. If I can’t explain this to my best friend, how could I explain my world to anyone else? I had to at least try.

At that moment, the spoon theory was born. I quickly grabbed every spoon on the table; hell, I grabbed spoons off of the other tables. I looked at her in the eyes and said “Here you go, you have Lupus”. She looked at me slightly confused, as anyone would when they are being handed a bouquet of spoons. The cold metal spoons clanked in my hands, as I grouped them together and shoved them into her hands.

I explained that the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn’t have to. The healthy have the luxury of a life without choices, a gift most people take for granted.

Most people start the day with unlimited amount of possibilities, and energy to do whatever they desire, especially young people. For the most part, they do not need to worry about the effects of their actions. So, for my explanation, I used spoons to convey this point. I wanted something for her to actually hold, for me to then take away, since most people who get sick feel a “loss” of a life they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case Lupus, being in control.

She grabbed the spoons with excitement. She didn’t understand what I was doing, but she is always up for a good time, so I guess she thought I was cracking a joke of some kind like I usually do when talking about touchy topics. Little did she know how serious I would become?

I asked her to count her spoons. She asked why, and I explained that when you are healthy you expect to have a never-ending supply of “spoons”. But when you have to now plan your day, you need to know exactly how many “spoons” you are starting with. It doesn’t guarantee that you might not lose some along the way, but at least it helps to know where you are starting. She counted out 12 spoons. She laughed and said she wanted more. I said no, and I knew right away that this little game would work, when she looked disappointed, and we hadn’t even started yet. I’ve wanted more “spoons” for years and haven’t found a way yet to get more, why should she? I also told her to always be conscious of how many she had, and not to drop them because she can never forget she has Lupus.

I asked her to list off the tasks of her day, including the most simple. As, she rattled off daily chores, or just fun things to do; I explained how each one would cost her a spoon. When she jumped right into getting ready for work as her first task of the morning, I cut her off and took away a spoon. I practically jumped down her throat. I said ” No! You don’t just get up. You have to crack open your eyes, and then realize you are late. You didn’t sleep well the night before. You have to crawl out of bed, and then you have to make your self something to eat before you can do anything else, because if you don’t, you can’t take your medicine, and if you don’t take your medicine you might as well give up all your spoons for today and tomorrow too.” I quickly took away a spoon and she realized she hasn’t even gotten dressed yet. Showering cost her spoon, just for washing her hair and shaving her legs. Reaching high and low that early in the morning could actually cost more than one spoon, but I figured I would give her a break; I didn’t want to scare her right away. Getting dressed was worth another spoon. I stopped her and broke down every task to show her how every little detail needs to be thought about. You cannot simply just throw clothes on when you are sick. I explained that I have to see what clothes I can physically put on, if my hands hurt that day buttons are out of the question. If I have bruises that day, I need to wear long sleeves, and if I have a fever I need a sweater to stay warm and so on. If my hair is falling out I need to spend more time to look presentable, and then you need to factor in another 5 minutes for feeling badly that it took you 2 hours to do all this.

I think she was starting to understand when she theoretically didn’t even get to work, and she was left with 6 spoons. I then explained to her that she needed to choose the rest of her day wisely, since when your “spoons” are gone, they are gone. Sometimes you can borrow against tomorrow’s “spoons”, but just think how hard tomorrow will be with less “spoons”. I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So, you do not want to run low on “spoons”, because you never know when you truly will need them. I didn’t want to depress her, but I needed to be realistic, and unfortunately being prepared for the worst is part of a real day for me.

We went through the rest of the day, and she slowly learned that skipping lunch would cost her a spoon, as well as standing on a train, or even typing at her computer too long. She was forced to make choices and think about things differently. Hypothetically, she had to choose not to run errands, so that she could eat dinner that night.

When we got to the end of her pretend day, she said she was hungry. I summarized that she had to eat dinner but she only had one spoon left. If she cooked, she wouldn’t have enough energy to clean the pots. If she went out for dinner, she might be too tired to drive home safely. Then I also explained, that I didn’t even bother to add into this game, that she was so nauseous, that cooking was probably out of the question anyway. So, she decided to make soup, it was easy. I then said it is only 7pm, you have the rest of the night but maybe end up with one spoon, so you can do something fun, or clean your apartment, or do chores, but you can't do it all.

I rarely see her emotional, so when I saw her upset I knew maybe I was getting through to her. I didn't want my friend to be upset, but at the same time I was happy to think finally maybe someone understood me a little bit. She had tears in her eyes and asked quietly "Christine, How do you do it? Do you really do this everyday?" I explained that some days were worse than others; some days I have more spoons than most. But I can never make it go away and I can't forget about it, I always have to think about it. I handed her a spoon I had been holding in reserve. I said simply, "I have learned to live life with an extra spoon in my pocket, in reserve. You need to always be prepared."

It's hard, the hardest thing I ever had to learn is to slow down, and not do everything. I fight this to this day. I hate feeling left out, having to choose to stay home, or to not get things done that I want to. I wanted her to feel that frustration. I wanted her to understand, that everything everyone else does comes so easy, but for me it is one hundred little jobs in one. I need to think about the weather, my temperature that day, and the whole day's plans before I can attack any one given thing. When other people can simply do things, I have to attack it and make a plan like I am strategizing a war. It is in that lifestyle, the difference between being sick and healthy. It is the beautiful ability to not think and just do. I miss that freedom. I miss never having to count "spoons".

After we were emotional and talked about this for a little while longer, I sensed she was sad. Maybe she finally understood. Maybe she realized that she never could truly and honestly say she understands. But at least now she might not complain so much when I can't go out for dinner some nights, or when I never seem to make it to her house and she always has to drive to mine. I gave her a hug when we walked out of the diner. I had the one spoon in my hand and I said "Don't worry. I see this as a blessing. I have been forced to think about everything I do. Do you know how many spoons people waste everyday? I don't have room for wasted time, or wasted "spoons" and I chose to spend this time with you."

Ever since this night, I have used the spoon theory to explain my life to many people. In fact, my family and friends refer to spoons all the time. It has been a code word for what I can and cannot do. Once people understand the spoon theory they seem to understand me better, but I also think they live their life a little differently too. I think it isn't just good for understanding Lupus, but anyone dealing with any disability or illness. Hopefully, they don't take so much for granted or their life in general. I give a piece of myself, in every sense of the word when I do anything. It has become an inside joke. I have become famous for saying to people jokingly that they should feel special when I spend time with them, because they have one of my “spoons”.

© Christine Miserandino

See more at: https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-%20theory/#sthash.a7MFFTiD.dpu

Emotions

1. **What fear can teach us?** Karen Thompson Walker | TEDGlobal 2012 - https://www.ted.com/talks/karen_thompson_walker_what_fear_can_teach_us#t-74665
2. **You aren't at the mercy of your emotions — your brain creates them**, Lisa Feldman Barrett | TED@IBM - https://www.ted.com/talks/lisa_feldman_barrett_you_aren_t_at_the_mercy_of_your_emotions_your_brain_creates_them?utm_source=facebook.com&utm_medium=social&utm_campaign=tedspread--a#t-15368
3. **What is in My Head and Why** - a post from Zona’s Zone (a blog by Zona, a lady with Chronic Fatigue Syndrome, Fibromyalgia and Multiple Chemical Sensitivity)

“… What I am going to tell you about is the emotional aspects of dealing with chronic illness, particularly chronic illnesses that the general public has not accepted as real yet. Some of these emotional reactions are directly caused by chemical and other exposures and some are from living day to day with the illnesses. I’m not going to separate them here.

Fear - While no one wants to talk about it this is a big issue. First these are illnesses which are often slow in being diagnosed. The symptoms are so many, so varied, so weird and often mimic other serious illnesses. It’s hard to imagine you can be this sick and not die. For people with MCS there is the real threat that you may get exposed to something that could kill you. Then there is fear of always being in pain and/or that you won’t be able to handle it. There is also fears of rejection and other things I’ll mention later. Fear is not fun to deal with!”

“…**Anger** - Ok so I don’t want to admit this one but I confess at times I feel angry. They say this is a stage of grief and indeed we have suffered great losses. Usually I don’t feel angry unless I’ve seen others who’ve been treated unfairly, or neglected, who have so many special needs but receive no help.

Typically it doesn't take along after becoming ill where you're unable to work and function normally before you find that there are other repercussions you hadn't even thought about like finances and friendships, having basic needs taken care of and learning that even if there is any assistance its sadly lacking and waaaay short of meeting the minimum necessities. This is especially true for young people who never got a start in the work place and had nothing paid into Social Security. It's also true for women who made their life's work their home and family. No one likes being dependent and now you've found there is nothing you can depend on."

"…**Envy** - Seeing green from time to time is normal too. It's not that you want to see family and friends do without too, it's more than you wish so badly you could do something too. I find this is especially true when people around me have made the assumption that I don't CARE to do this or that, that I somehow LIKE being ill. It's like a friend told me once. She envied the little old gray-haired lady next door who would go out on jogs and do yardwork!"

"… **Discouragement** -I've read all the research, tried all the suggestions, pushed myself, let myself rest and NOTHING seems to make much difference. Friends don't understand why I won't come to their house, family thinks I'm faking it. If I do more to take care of myself someone thinks I'm selfish or neglecting my family. If I take care of everyone else first I get sicker. Even with working there's a problem. What little assistance is there for some people can be stripped to nothing if they try to help themselves a little. It's all of nothing. Discouragement is what we face daily."

"… **Depression** - Some people with these chronic illnesses suffer greatly from depression. They get even more depressed listening to people saying that they're ill BECAUSE their depressed. Like they're not really ill, only depressed therefore THEY should be able to do something about it. This simply is NOT true. These illnesses affect the brain and brain function. Some of the medications needed do too. Top that off with how much they've had to give up to remain at the level they are at and you can surely see why anyone would be depressed! Being told you're depressed is not encouraging or uplifting either."

"…**Loneliness** - I can't begin to tell you in words about the aloneness and loneliness those of us who are fairly homebound feel. Loneliness and aloneness are different. We feel both. No matter how many others you may know with the same illness you still are very much alone in your own body. All illnesses are like this. It does help to be part of a support group of some sort though. Then there is the loneliness. We're isolated, unable to go to social functions without paying a major price with our health, for some life risking. After a while friends fall away as you can no longer do things with them. Some get sick of hearing about all the symptoms or frustrated with not being able to help. Most public meeting places are filled with things unsafe for people with MCS. Most people with CFS or FM don't have the stamina to participate. So over time they find themselves more and more apart from the rest of the world. Days on end without a change in scenery can give you cabin fever plus! You get stir crazy but don't even have energy to stir! You may crave to have a friend come visit only to find that when they come you get so wiped out from trying to behave 'healthy' that you wish they'd cut the visit short. You fear friends and family will take that wrong and you don't want to hurt them either."

"…**Grief** - After the initial shock of being ill comes a time of grieving. There are real losses encountered. Loss of health, jobs, abilities, money, lifestyle and often friendships and other relationships. There's a loss of income, loss of enjoyments, and loss of freedom. Chronic illnesses especially those like these that affect every part of your being cause you to feel like you've lost your old self. With the recognition of those losses comes a time of mourning. Like other illnesses a period of feeling angry follows too. Wanting to fight back. These losses are very real and some are forever."

"…**Rejection** - I'm afraid that way too often people who are disabled, unable to work or participate, having weird sounding invisible symptoms end up feeling rejected. Sometimes that is because they are being rejected. We live in a society who values most productivity. Most self-worth comes from what you 'do' and we can't do much. Sometimes we are shunned, sometimes actually told off! When others behave like this I try to remember that they are afraid. Our illness scares them. It exposes their own vulnerability and people feel very comfortable when they feel vulnerable. We are a reminder to them that nothing in life is sure, nothing forever. So, it is often easier for them to deny that we are really ill than to face that possibility themselves. Sometimes the rejection comes from indirect reasons lack of income. But whatever the reason it hurts to feel rejected. Sometimes Christians who are ill even feel rejected by their own churches."

"…**Worthlessness** - In a society where the first thing people ask you is "what do you do?", meaning 'for a living', it's quite easy to feel like you do nothing when you're ill. Many folks with these illnesses don't have the strength or energy to even do ordinary household chores let alone hold a job outside the home too. Even those who don't have the fatigue problem still are very limited because of having to avoid chemicals and dust and mold and other things. So, the 'what do you do' question is quite perplexing.

Others seem to judge us by that standard too. So, what is our worth? All of us who are ill go through this questioning at least periodically, and especially during long periods of 'crashes'. We don't even know who we are anymore. We're sure not like we were pre-illness. We can't play with our kids like we used to, we can't even go out with our spouses. And we feel like we're always needing something, some help. We feel very dependent on others and sometimes we feel that others resent that. We don't want to ask for too much because after all what do we have to offer in return? We live in a society that wants to eliminate imperfect babies and aid chronically ill people to kill themselves, because after all what kind of life could they possibly have???

"…**Anxious** - I get some pretty bizarre symptoms, some of them affect my thinking and some produce anxiety all by themselves. Anxiety is nerve wracking! It's no fun feeling anxious. You feel like you somehow need to guard against the next attack yet have no idea what direction it may come from nor what it may cause. Yes, worry is related to anxiety but while worry may give you wrinkles, anxiety gives you the jitters. Some symptoms produce anxiety like those that interfere with normal breathing or cause rapid heartbeat. Others cause it indirectly, especially pre-diagnosis or new symptoms. With invisible illnesses that are not yet understood or even acknowledged by most people the symptoms are often confused with other serious, life threatening conditions. That makes us anxious too."

"…**Confused** - Oh boy do I get confused sometimes. I wonder, "Am I nuts? Is this all in my head like so many try to say it is?" I wonder what I should try next, do next. I find myself much like others in this state, questioning the whys of life, wondering what I should do next. And the big thing is 'who to listen to?'. There's so many conflicting reports and so many contrary attitudes and opinions even in Christian quarters. We Christians don't really talk too much on handling adversity and usually get the message that it's just not kosher to talk about it or at best to talk with a stiff upper lip and a smile on our face. Sometimes that's not easy to do."

"…**Weariness** - sometimes we get just plain weary. I know I do. It's more than the crushing fatigue and heaviness the illness causes. It's a weariness of spirit. I get so tired of having to struggle just to make it through the day. I get tired of dealing with 'illness issues', doctors and just plain hearing about illness. Yet it's never far from my mind because there it is before my face where I have to deal with it. Some symptoms are pretty hard to ignore like cognitive ones. I get weary."

"…There is much more I could say on this subject but I suspect you have read enough. Next time you see someone with a chronic illness talk to them and listen. Put yourself in their shoes even if that means you have to follow through one of their days to understand better. And most importantly, don't judge them."

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Module 1 – Foundation

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