



Shared decision-making in HD

A secret and intimate **crystallization**



Pr. Z **JEDD**, MD, PhD

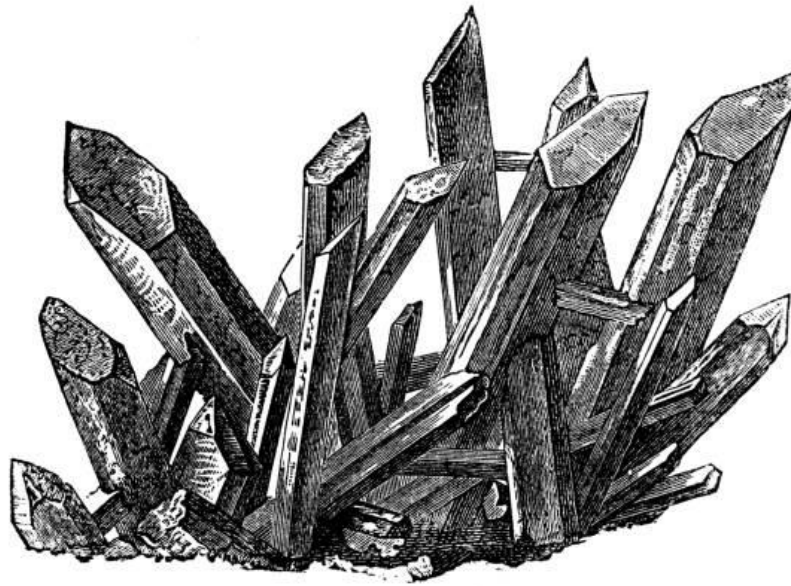
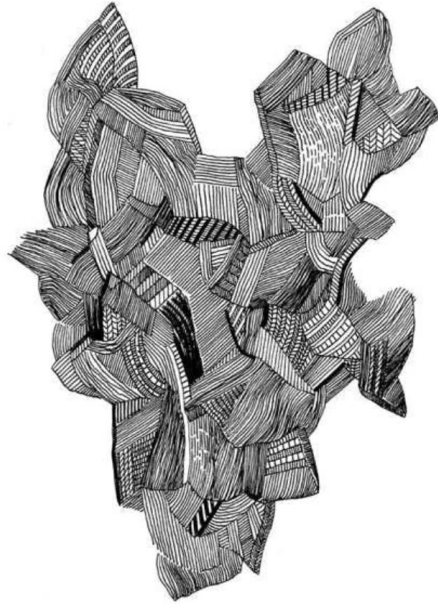


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

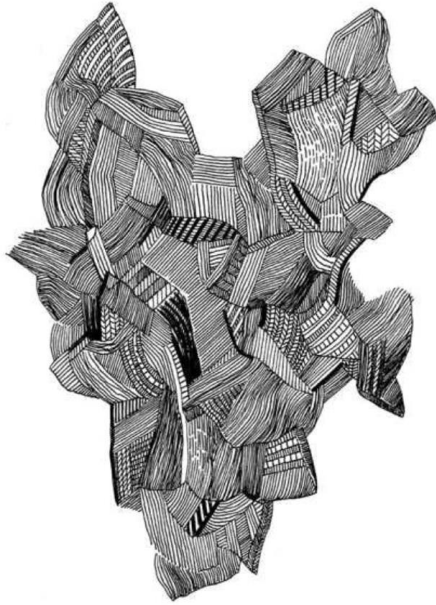
Crystallization *Crystallization* \kɹɪstəˈlɪzəˈʃjən\ noun.

(Chemistry, Geology) * A **slow** and **gradual process** by which the particles of a substance, in a gaseous state or dissolved in a liquid, are **drawn together** by their **own mutual attractions** to form a **solid** body with a **regular and defined structure**.

The formation of a crystal depends on various factors such as temperature, **pressure**, and evaporation **time**.

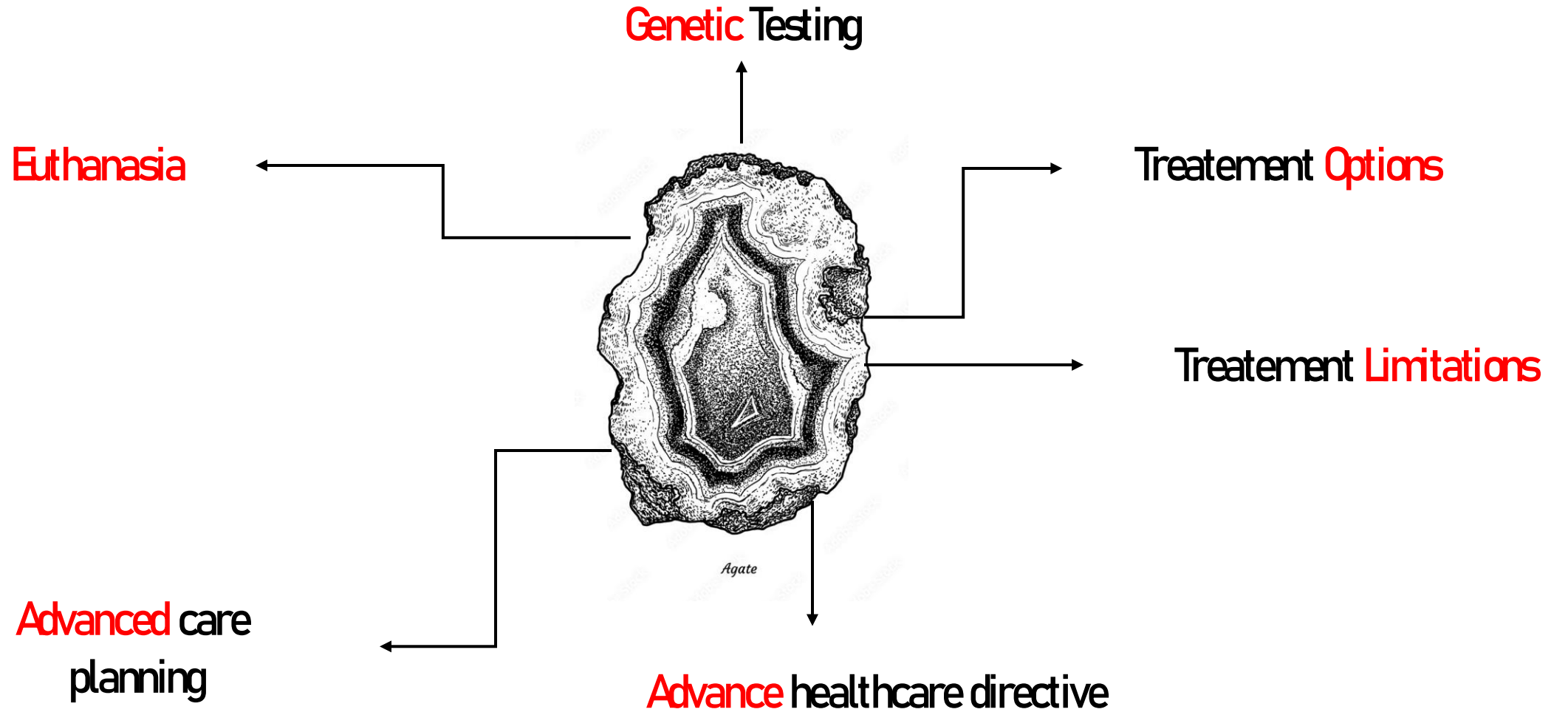


SUMMARY



SUMMARY

- * Introduction
- * Pitfalls
- * Family caregivers
- * Conclusion & Recommendations



- Diagnostic confirmation
- Genetic screening
- Preimplantation genetic diagnosis (PGD)

Genetic Testing

- Informations about the disease/symptoms
- Exposing alternatives
- Explain adverse effects
- Adjusting therapy to lifestyle, fears & values

Euthanasia

- In the contries where it is available
- Within the limits of the law
- to a greater or lesser extent, active or passive*
- Performed by the doctor
- Performed by the patient - Assisted dying
- Continuous deep sedation at the end of life
- Who, Where, When... ?

Treatment Options

Treatment Limitations

- Tube feeding
- ICU admission - intubation - Resuscitation
- Life support
- Anything the patient would consider unworthy



Agate

Advanced care planning

Unformal | Thinking ahead

- Personal values & beliefs
- Designation of a representative
- Treatment preferences
- Wishes regarding the body after death
- Requests concerning euthanasia
- Funeral wishes

Advance healthcare directive

Formalized | Legal value

- **Care** → From Latin *carus* → “of value”

The other person is **always** a being of value,
Capable of affecting/moving us, of becoming close and dear.

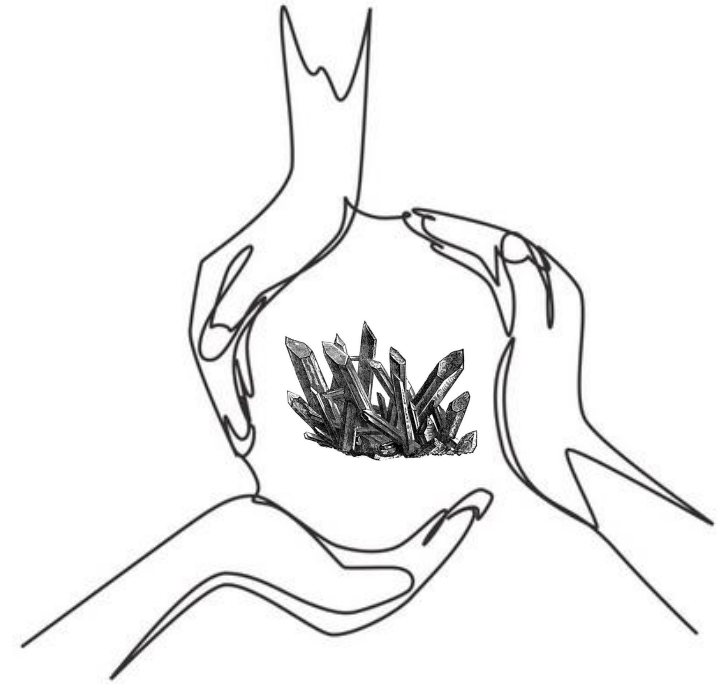
From whom we must provide care (to **take care**)

But also someone we must **care about** (to care)

Hearing a complaint means listening to it, analyzing it
with the aim of finding a solution.

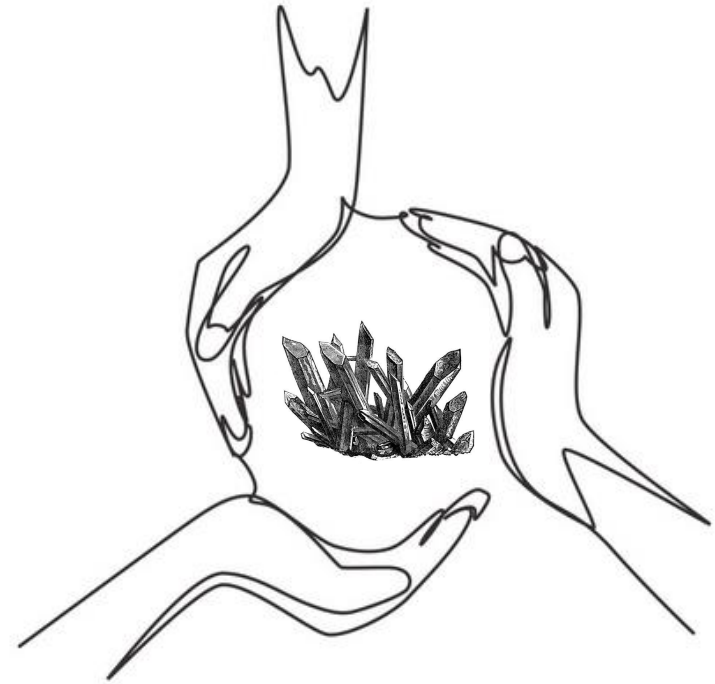
» Thus, “care” complements “cure”

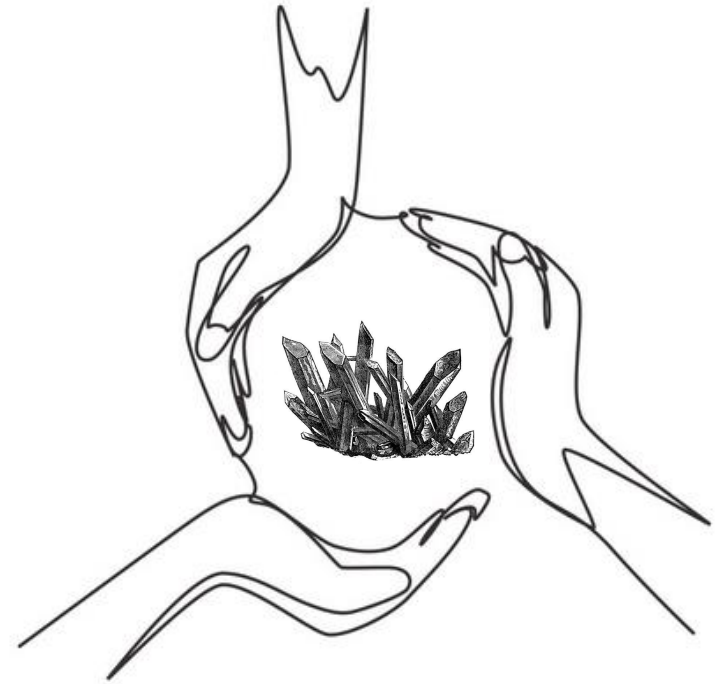
→ *To heal sometimes, to relieve often, **to comfort always***



... From the perspective of **care**

DOCTOR
↓↑
PATIENT



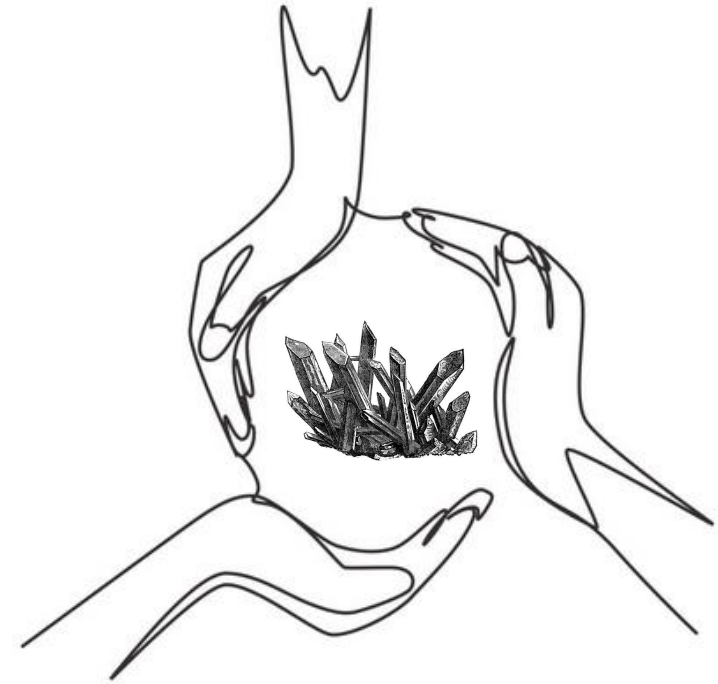


HUMAN
With scientific – academic –
theoretical – objective – knowledge



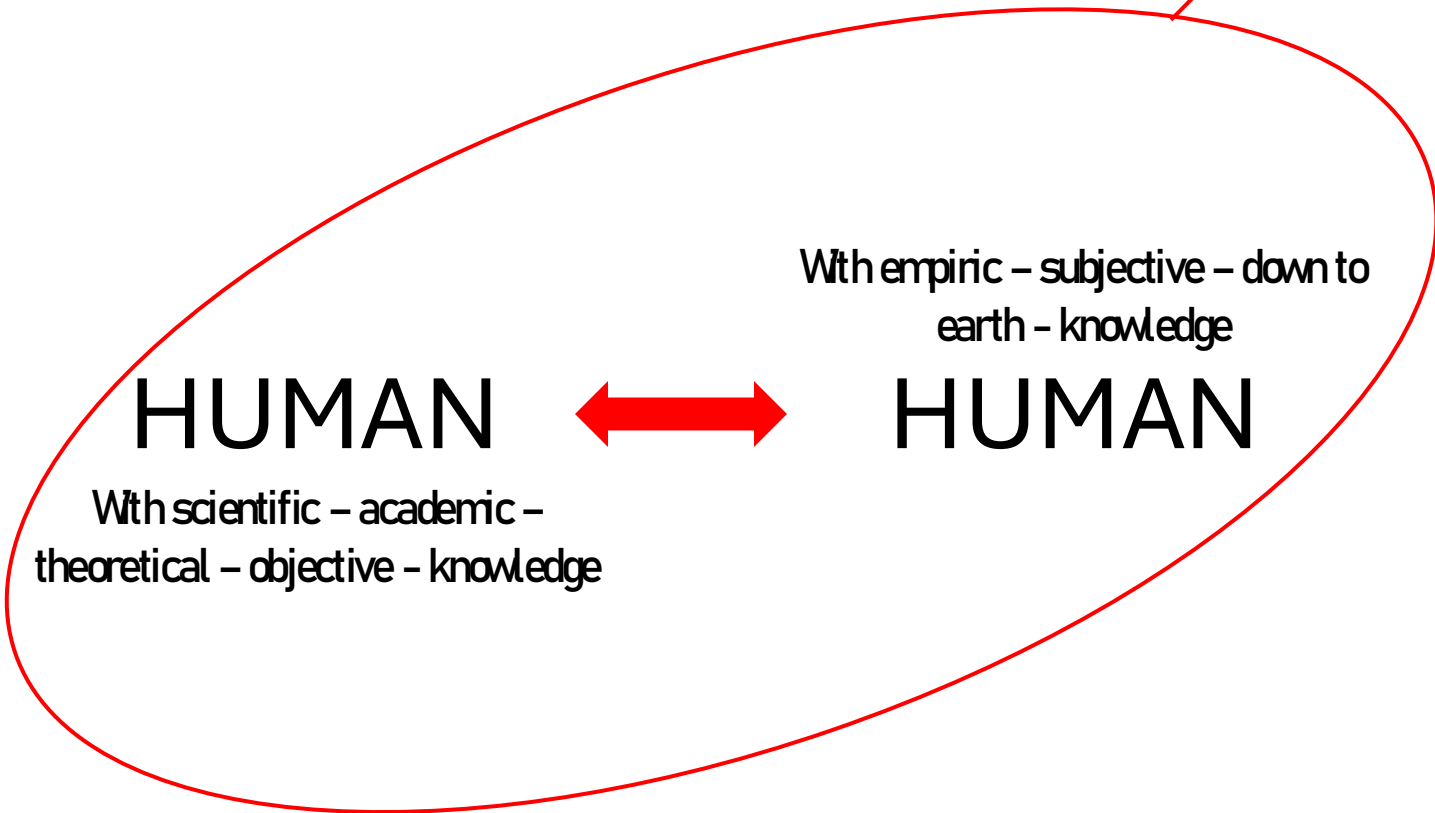
With empiric – subjective – down to
earth – knowledge

HUMAN



MULTIDISCIPLINARY TEAM

Shifting perspective



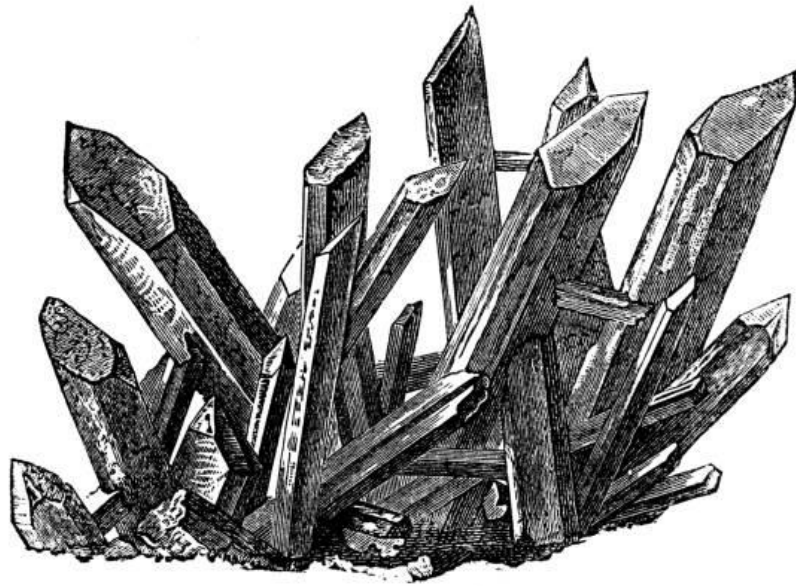


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Pitfalls

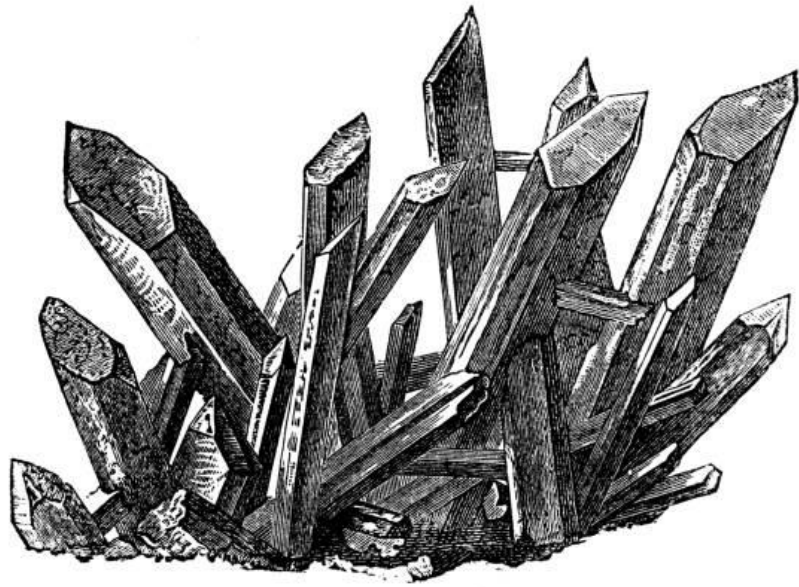


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

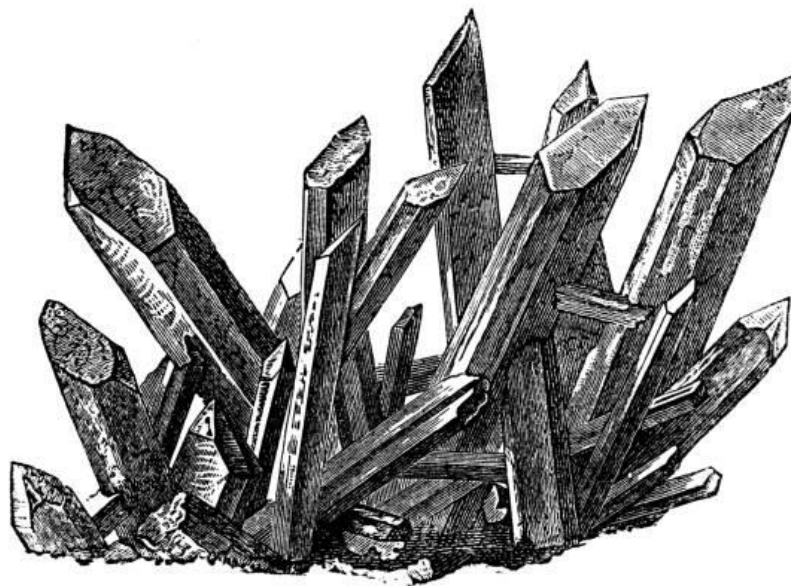
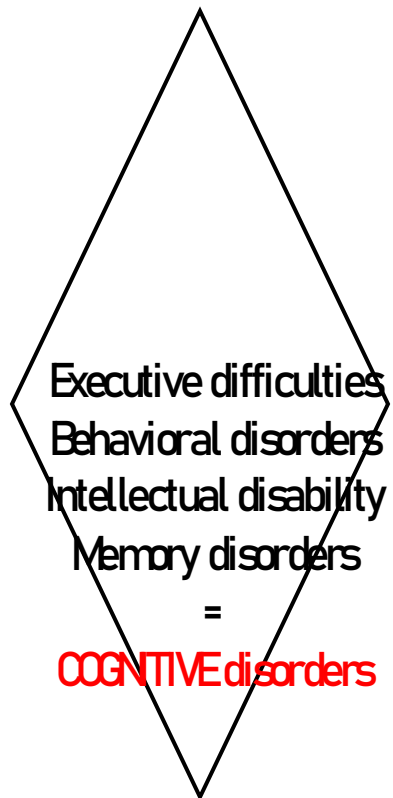


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

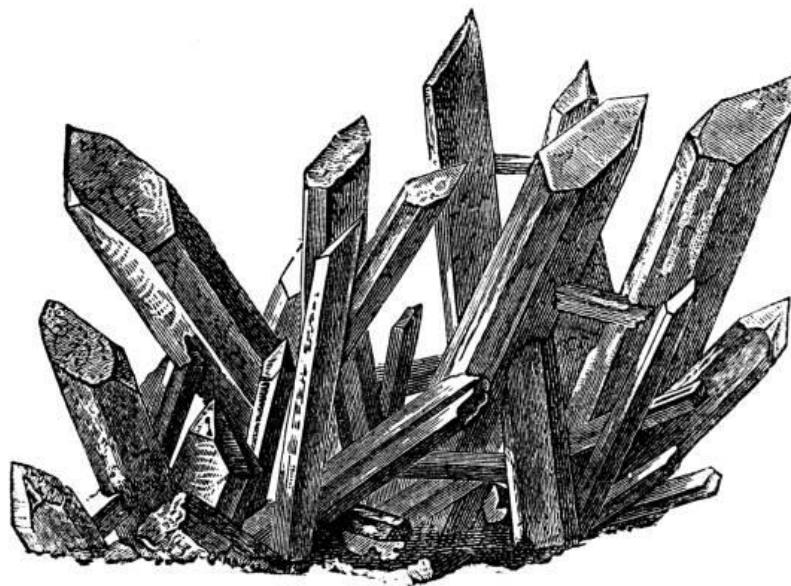
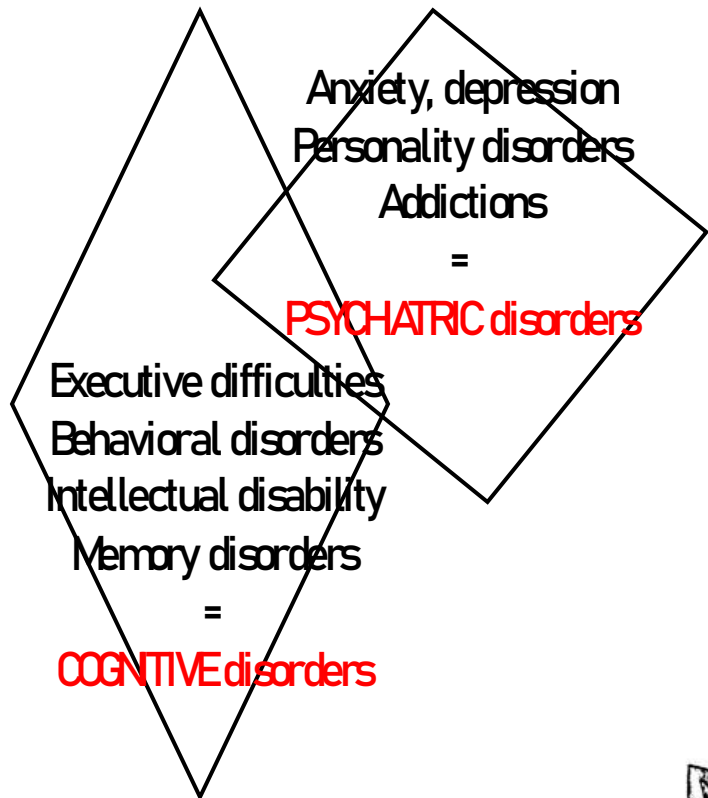


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

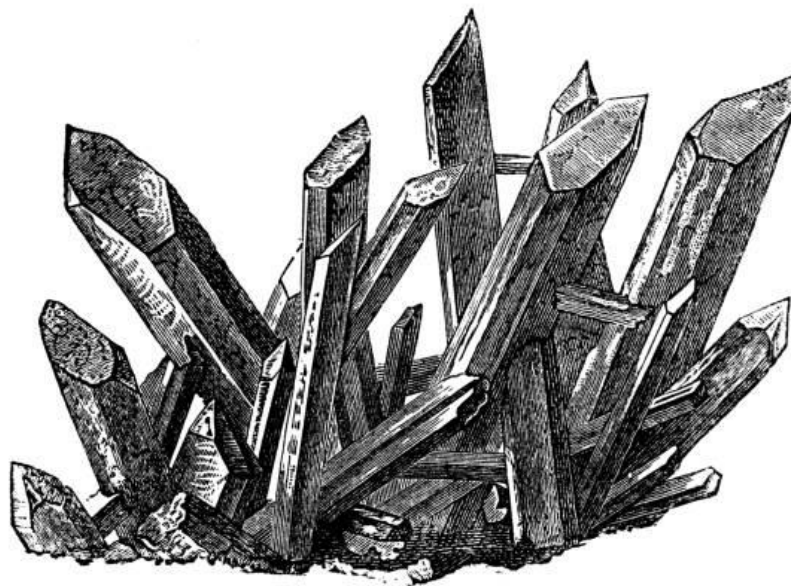
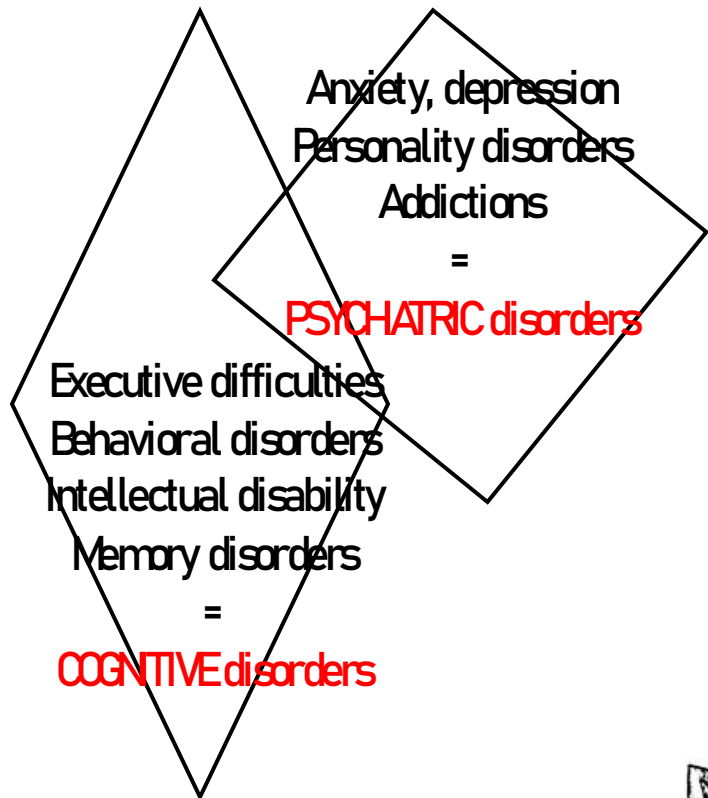


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



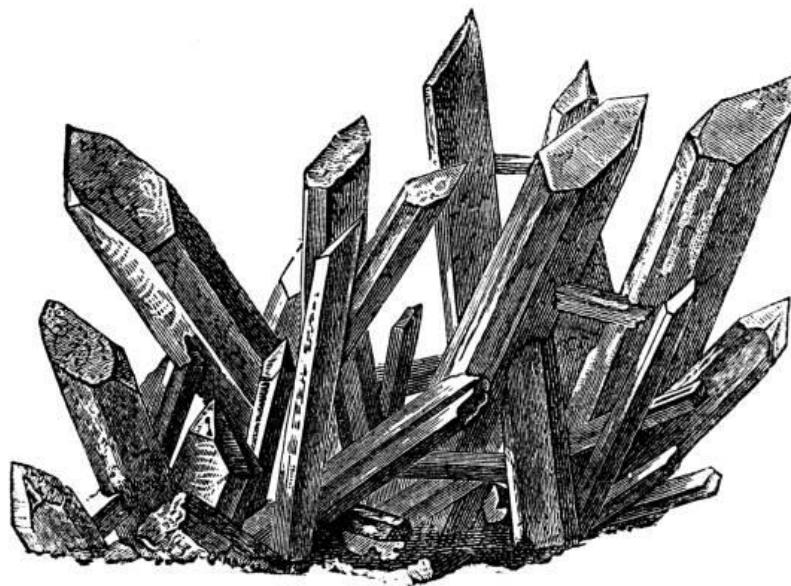
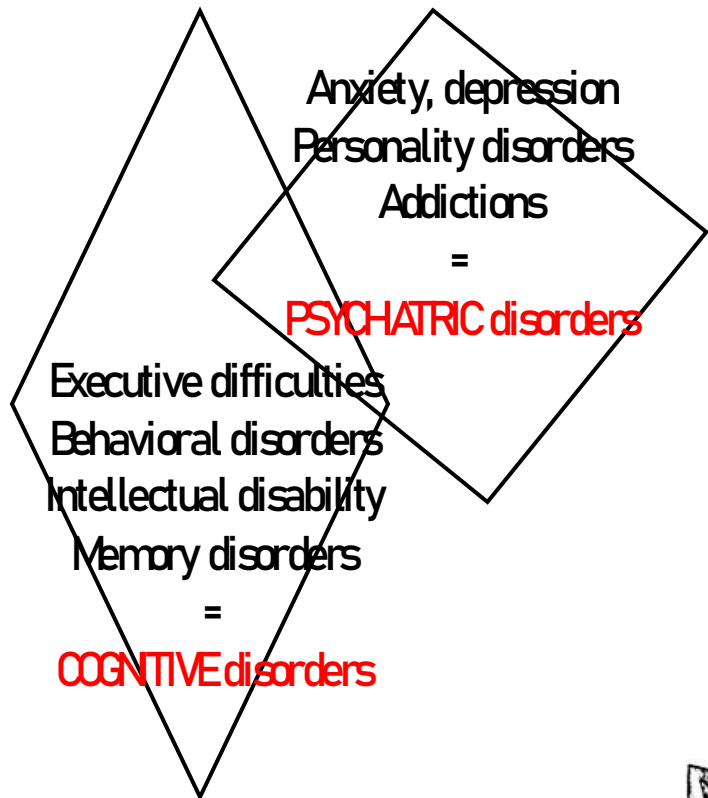
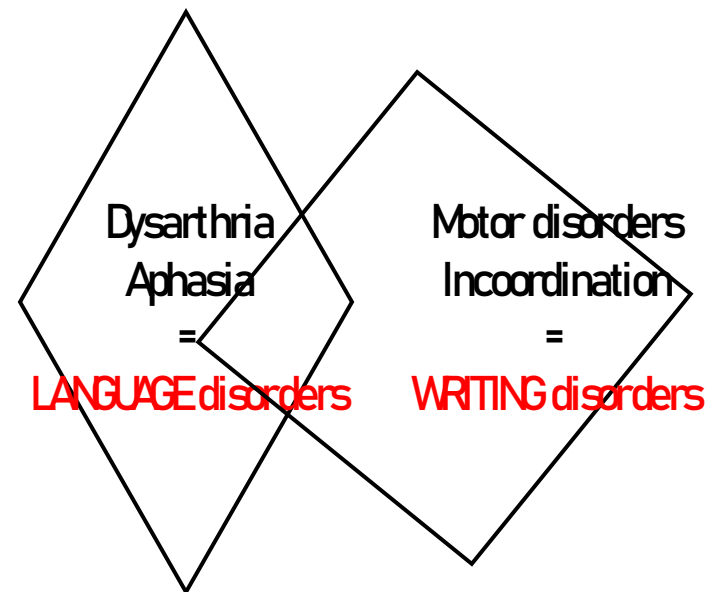


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



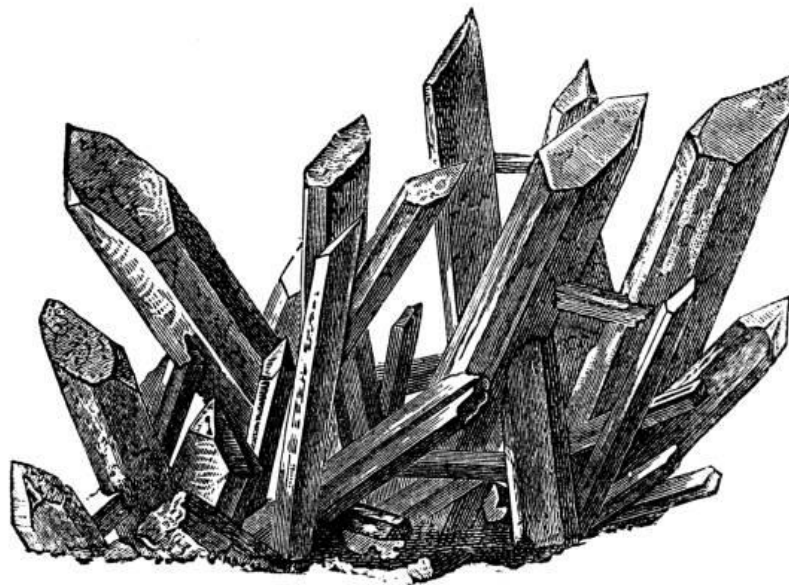
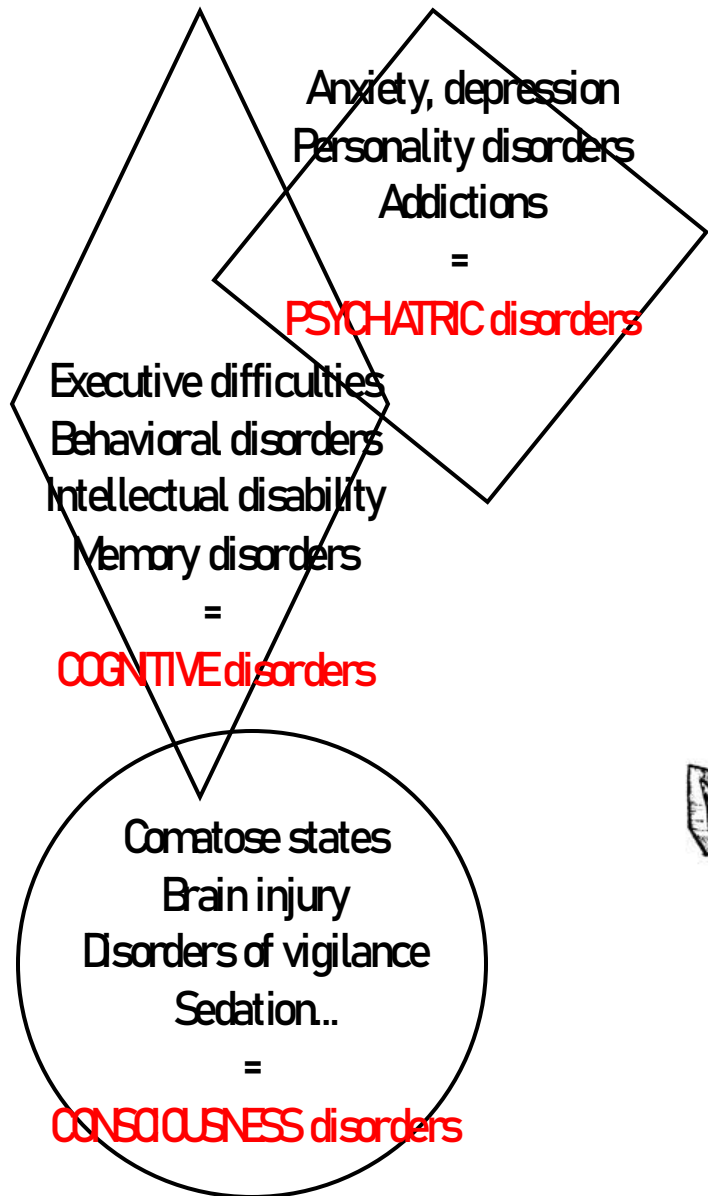
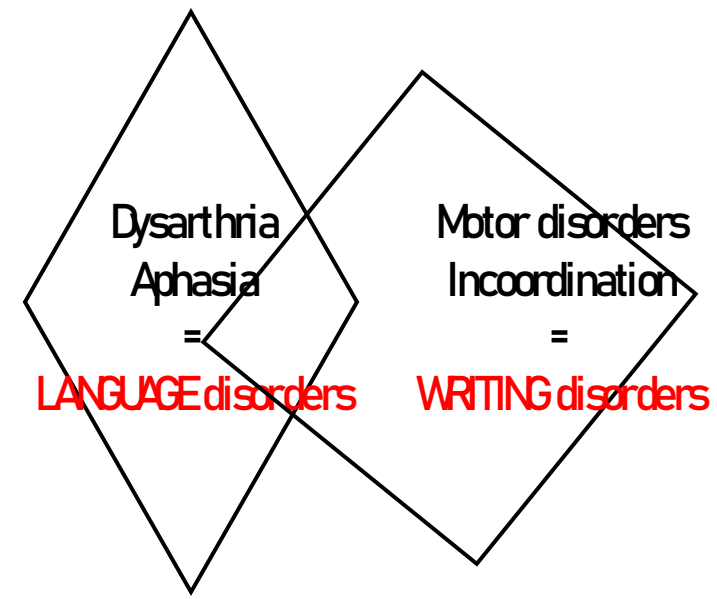


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



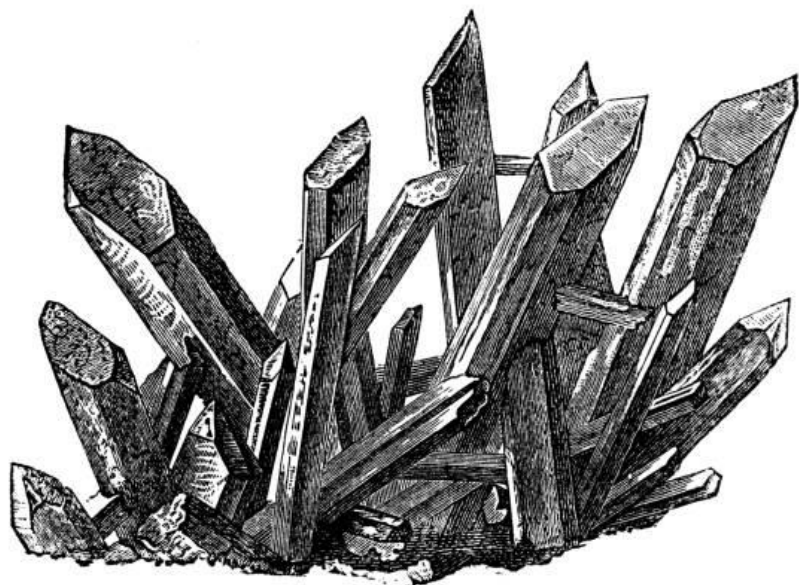
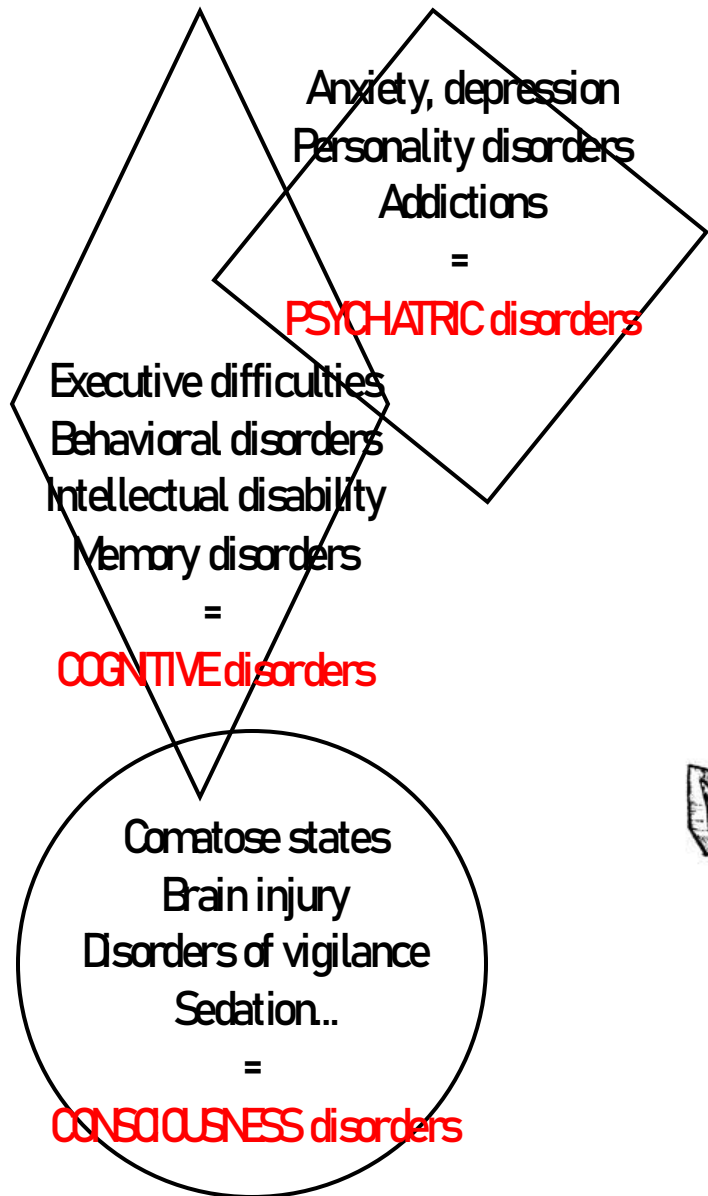
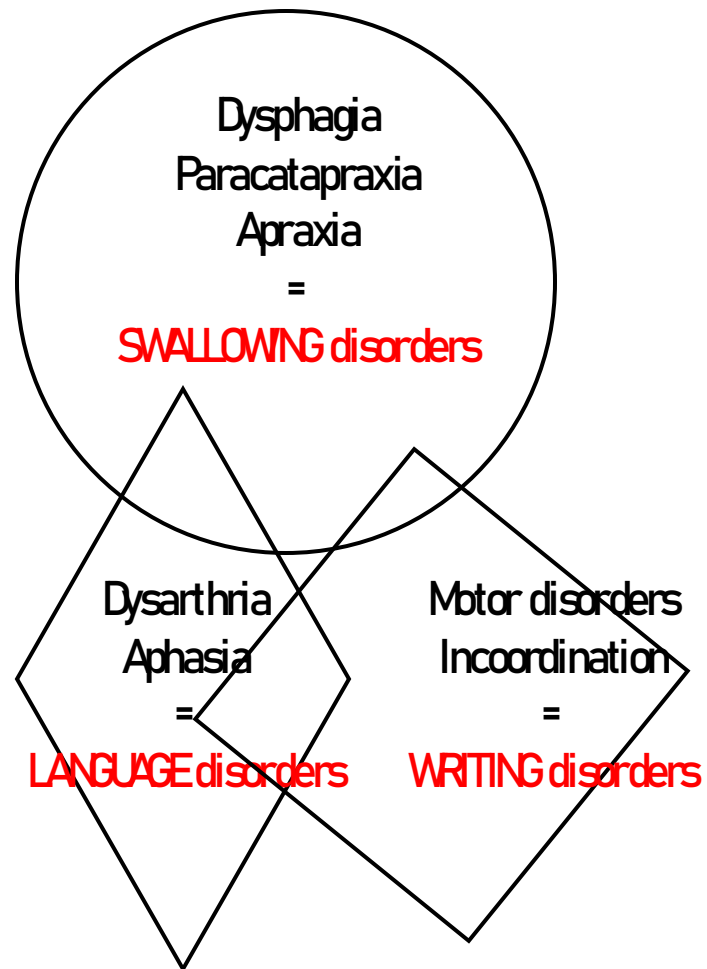


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



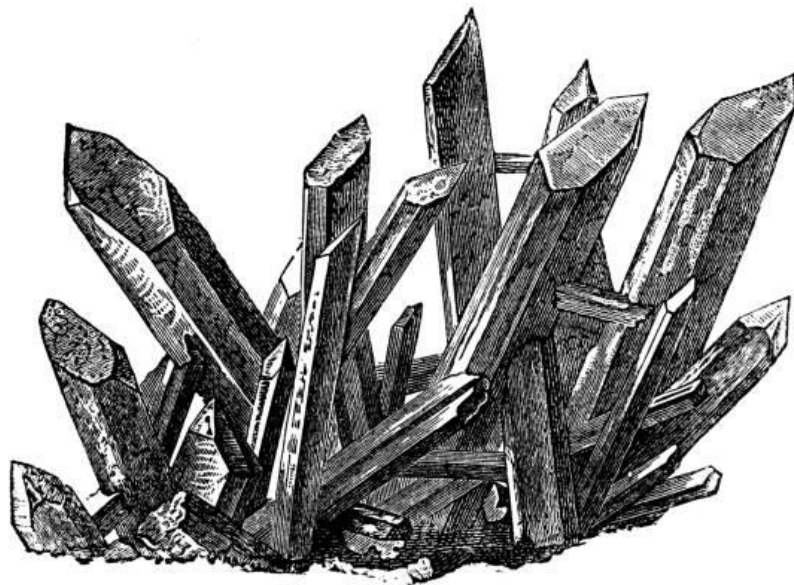
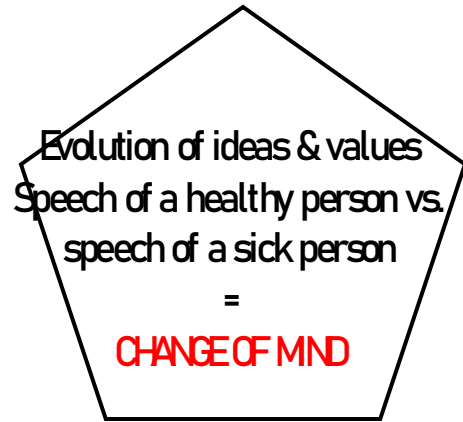
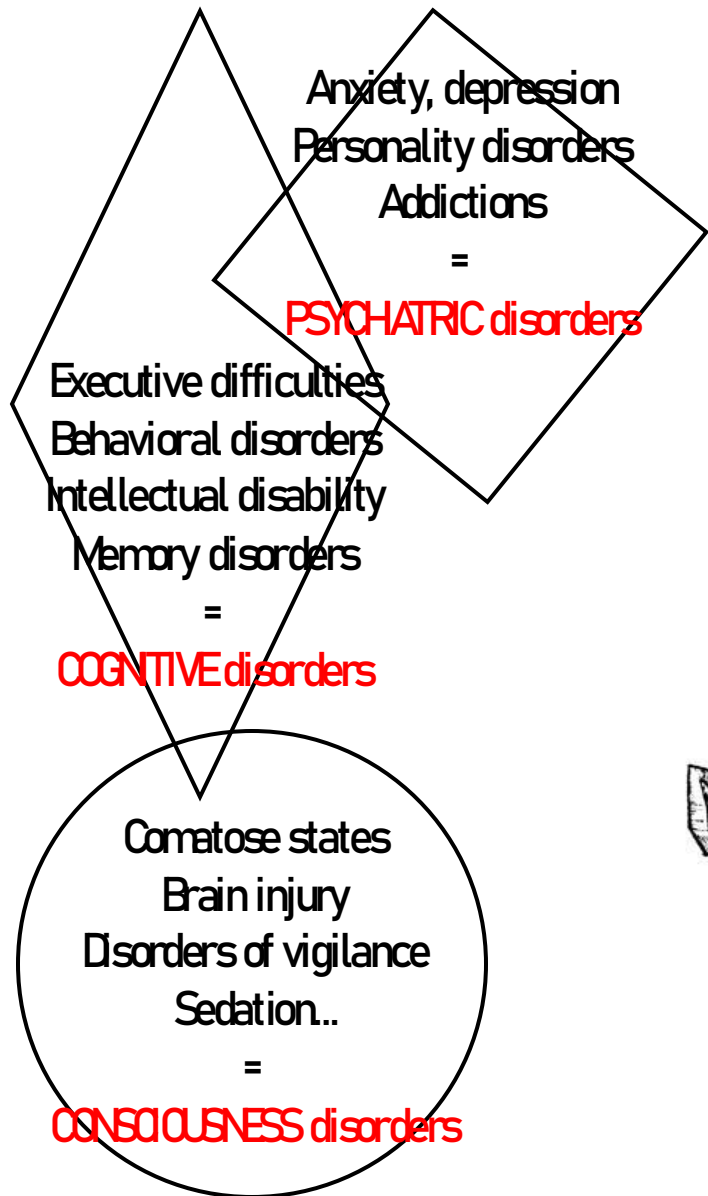
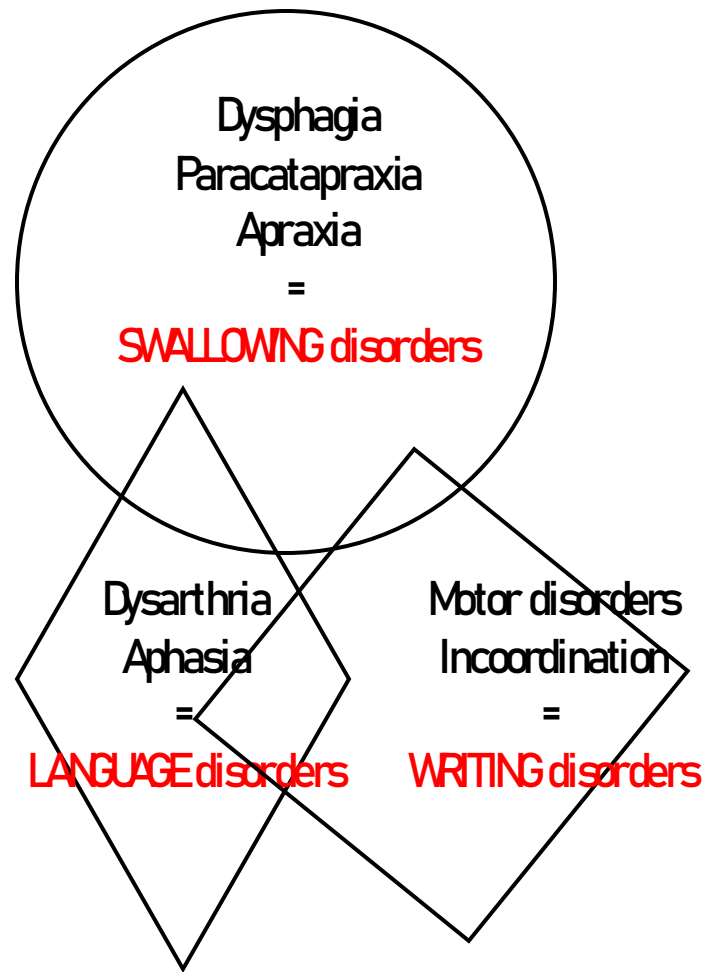


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



Anxiety, depression
Personality disorders
Addictions

=

PSYCHIATRIC disorders

Executive difficulties
Behavioral disorders
Intellectual disability
Memory disorders

=

COGNITIVE disorders

Comatose states
Brain injury
Disorders of vigilance
Sedation..

=

CONSCIOUSNESS disorders

Evolution of ideas & values
Speech of a healthy person vs.
speech of a sick person

=

CHANGE OF MIND

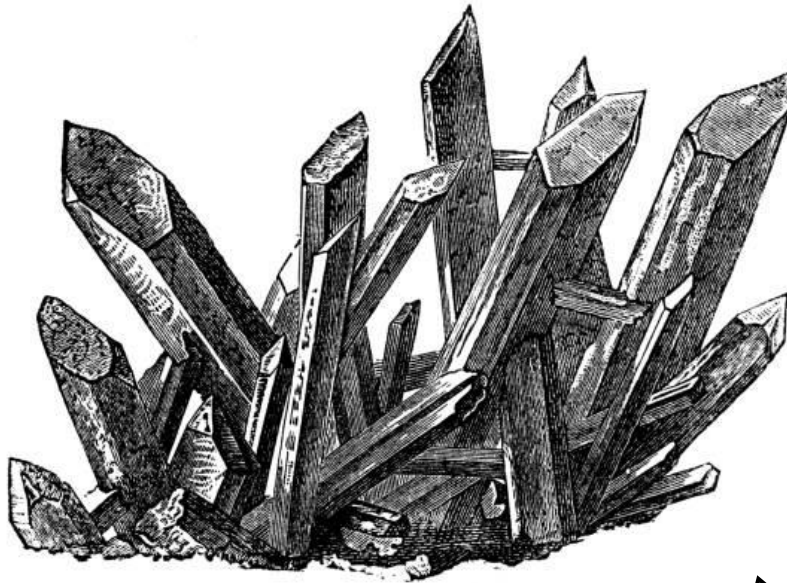


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Dysphagia
Paracatapraxia
Apraxia

=

SWALLOWING disorders

Dysarthria
Aphasia

=

LANGUAGE disorders

Motor disorders
Incoordination

=

WRITING disorders

Blindness
Visual impairment
Deafness

=

NEUROSENSORY disorders

Anxiety, depression
 Personality disorders
 Addictions
 =
PSYCHATRIC disorders

Executive difficulties
 Behavioral disorders
 Intellectual disability
 Memory disorders
 =
COGNITIVE disorders

Comatose states
 Brain injury
 Disorders of vigilance
 Sedation...
 =
CONSCIOUSNESS disorders

Evolution of ideas & values
 Speech of a healthy person vs.
 speech of a sick person
 =
CHANGE OF MIND

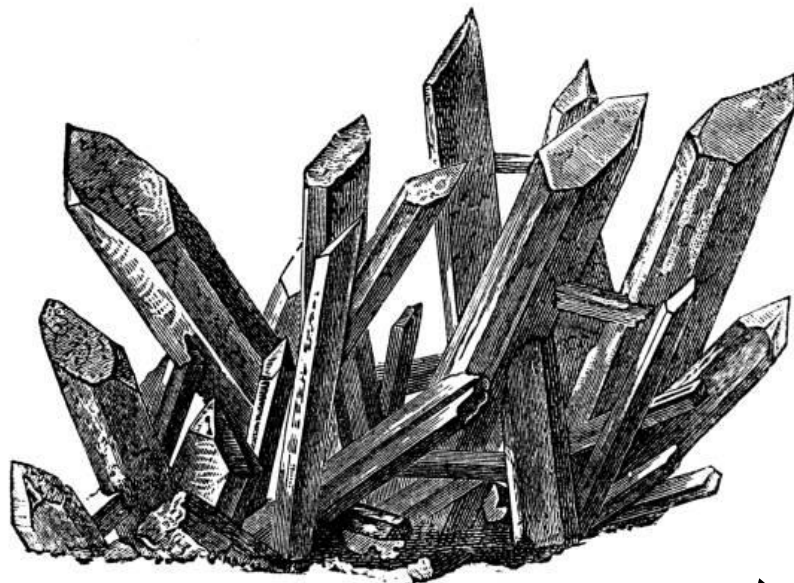


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

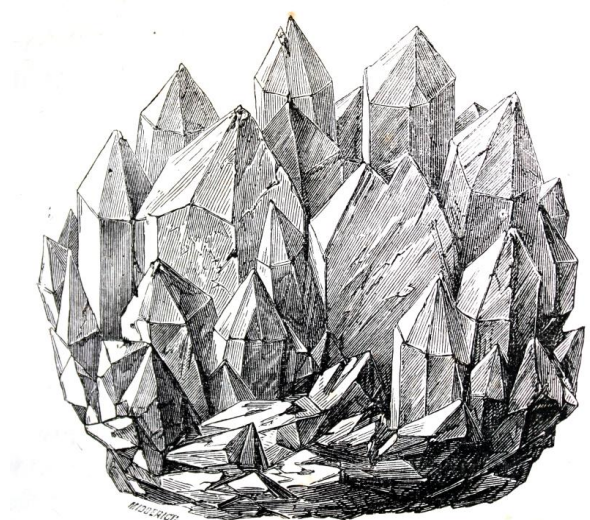
Wishes, projections &
 expectations of relatives
 =
**INFLUENCE OF
 FAMILY/ENTOURAGE**

Dysphagia
 Paracatapraxia
 Apraxia
 =
SWALLOWING disorders

Dysarthria
 Aphasia
 =
LANGUAGE disorders

Motor disorders
 Incoordination
 =
WRITING disorders

Blindness
 Visual impairment
 Deafness
 =
NEUROSENSORY disorders



Family caregivers..
A crystal to be **refined**

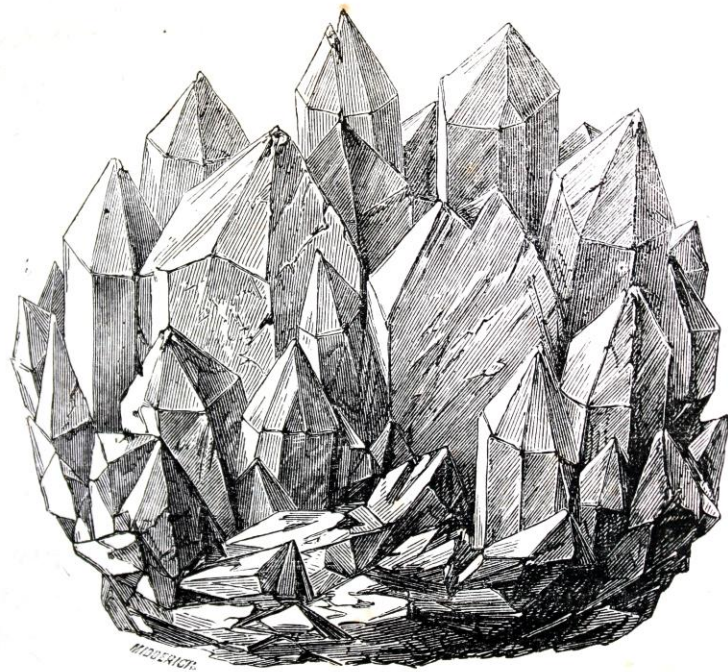


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

+Spends a **lot of time** with the patient

Unique and powerful relationship, often irreplaceable

- *It is with those closest to us that conflicts can be the sharpest (no one is a prophet in their own land).*

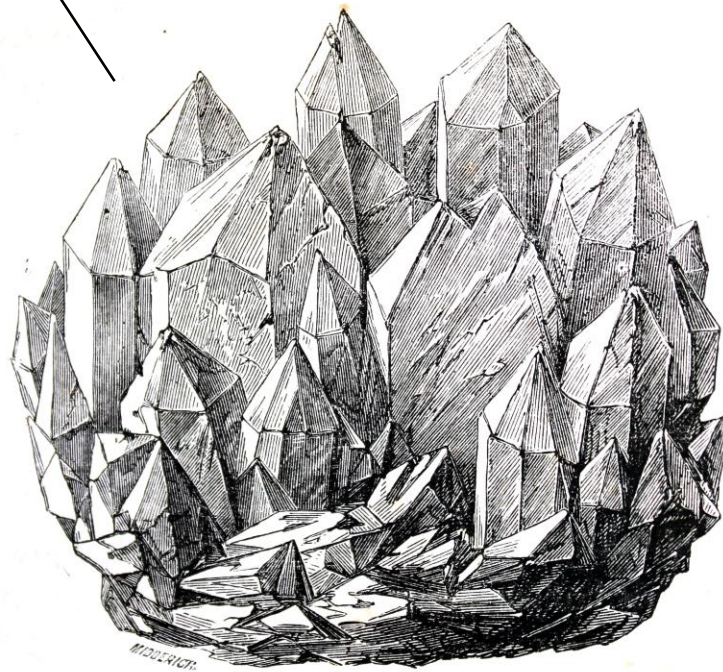


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

+Spends a **lot of time** with the patient

Unique and powerful relationship, often irreplaceable

- *It is with those closest to us that conflicts can be the sharpest (no one is a prophet in their own land).*

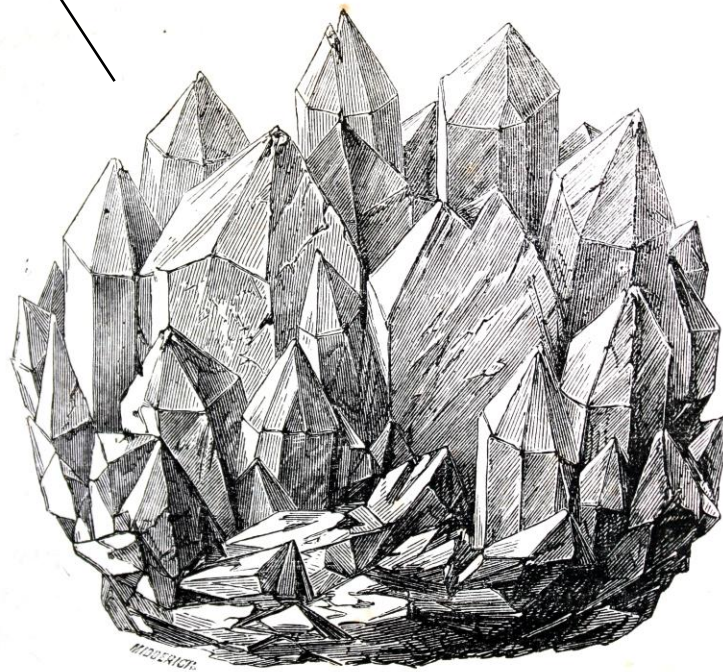


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

+ Extensive practical and **empirical experience** of the disease

Often provides useful tips and insights

- *They are experts in one patient, not necessarily in the disease itself / resistance to change / what works at one moment may not work later / need to see the long term*

+Spends a **lot of time** with the patient

Unique and powerful relationship, often irreplaceable

- *It is with those closest to us that conflicts can be the sharpest (no one is a prophet in their own land).*

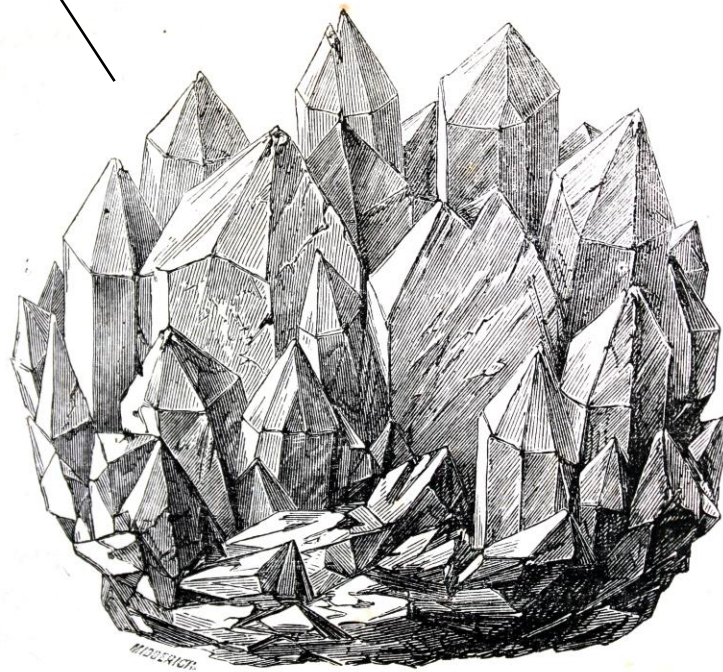


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

+ Valuable knowledge of the patient's **context** and real-life situation
Essential link in coordinating care and transmitting information

- *Everyone must be able to play their role / risk of overinvestment, exhaustion / tensions with other professionals*

+ Extensive practical and **empirical experience** of the disease

Often provides useful tips and insights

- *They are experts in one patient, not necessarily in the disease itself / resistance to change / what works at one moment may not work later / need to see the long term*

+Spends a **lot of time** with the patient
Unique and powerful relationship, often irreplaceable
- *It is with those closest to us that conflicts can be the sharpest (no one is a prophet in their own land).*

+ An **integral part of the patient's life** / strong subjective experience
Provides an anchor and stability for the patient & helps the healthcare team understand the situation
- *May feel criticized, blamed, or lack objectivity (e.g. in cases of behavioral disorders)*
May also be directly affected by the disease (children, ...).

+ Valuable knowledge of the patient's **context** and real-life situation
Essential link in coordinating care and transmitting information
- *Everyone must be able to play their role / risk of overinvestment, exhaustion / tensions with other professionals*

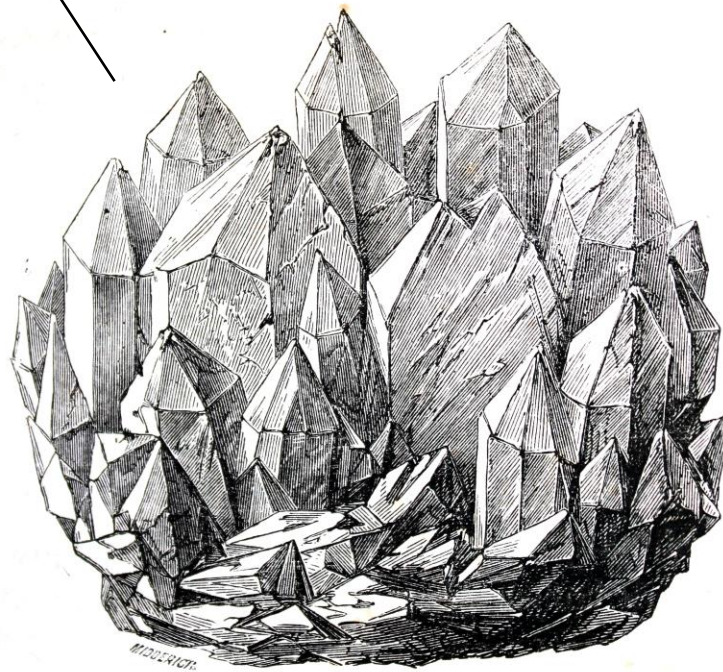


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

+ Extensive practical and **empirical experience** of the disease
Often provides useful tips and insights
- *They are experts in one patient, not necessarily in the disease itself / resistance to change / what works at one moment may not work later / need to see the long term*

- +Spends a **lot of time** with the patient
- Unique and powerful relationship, often irreplaceable
- *It is with those closest to us that conflicts can be the sharpest (no one is a prophet in their own land).*

- +An **integral part of the patient's life** / strong subjective experience
- Provides an anchor and stability for the patient & helps the healthcare team understand the situation
- *May feel criticized, blamed, or lack objectivity (e.g. in cases of behavioral disorders)*
- May also be directly affected by the disease (children, ...).*

- +Valuable knowledge of the patient's **context** and real-life situation
- Essential link in coordinating care and transmitting information
- *Everyone must be able to play their role / risk of overinvestment, exhaustion / tensions with other professionals*

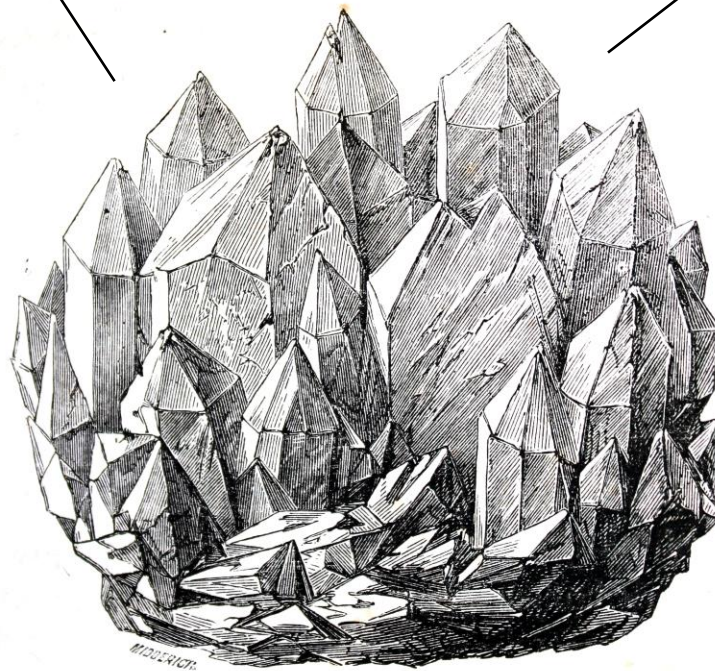


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

- +**Intimate** and profound knowledge of the patient, including before illness
- Knows the patient's life, history, and values
- *The discourse, attitude, and choices of a sick person may change / the caregiver's "fights" may differ from those of the patient.*

- +Extensive practical and **empirical experience** of the disease
- Often provides useful tips and insights
- *They are experts in one patient, not necessarily in the disease itself / resistance to change / what works at one moment may not work later / need to see the long term*

+Spends a **lot of time** with the patient
Unique and powerful relationship, often irreplaceable
- It is with those closest to us that conflicts can be the sharpest (no one is a prophet in their own land).

+An **integral part of the patient's life** / strong subjective experience
Provides an anchor and stability for the patient & helps the healthcare team understand the situation
- May feel criticized, blamed, or lack objectivity (e.g. in cases of behavioral disorders)
May also be directly affected by the disease (children, ...).

+Valuable knowledge of the patient's **context** and real-life situation
Essential link in coordinating care and transmitting information
- Everyone must be able to play their role / risk of overinvestment, exhaustion / tensions with other professionals

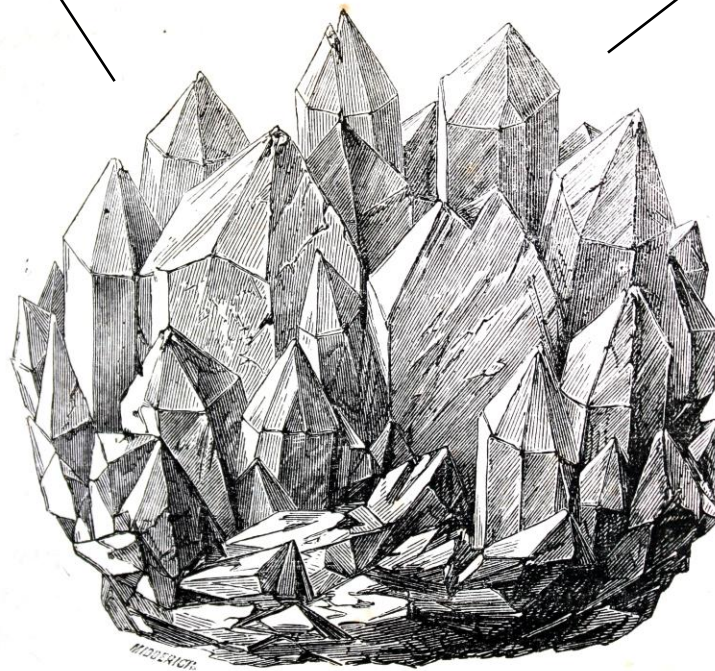


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

+**Intimate** and profound knowledge of the patient, including before illness
Knows the patient's life, history, and values
- The discourse, attitude, and choices of a sick person may change / the caregiver's "fights" may differ from those of the patient.

+Extensive practical and **empirical experience** of the disease
Often provides useful tips and insights
- They are experts in one patient, not necessarily in the disease itself / resistance to change / what works at one moment may not work later / need to see the long term

+**Emotional support** often unconditional
Reduces patient distress and anxiety
- Often neglects their own well-being, becomes socially isolated, has difficulty letting go frustration..

+Spends a **lot of time** with the patient
Unique and powerful relationship, often irreplaceable
- It is with those closest to us that conflicts can be the sharpest (no one is a prophet in their own land).

+An **integral part of the patient's life** / strong subjective experience
Provides an anchor and stability for the patient & helps the healthcare team understand the situation
- May feel criticized, blamed, or lack objectivity (e.g. in cases of behavioral disorders)
May also be directly affected by the disease (children, ...).

+Valuable knowledge of the patient's **context** and real-life situation
Essential link in coordinating care and transmitting information
- Everyone must be able to play their role / risk of overinvestment, exhaustion / tensions with other professionals

+Seeks **the best** for the patient
When the patient is not always able to do so
- Sometimes in an "unrealistic" way or even against the wishes of the patient... or themselves

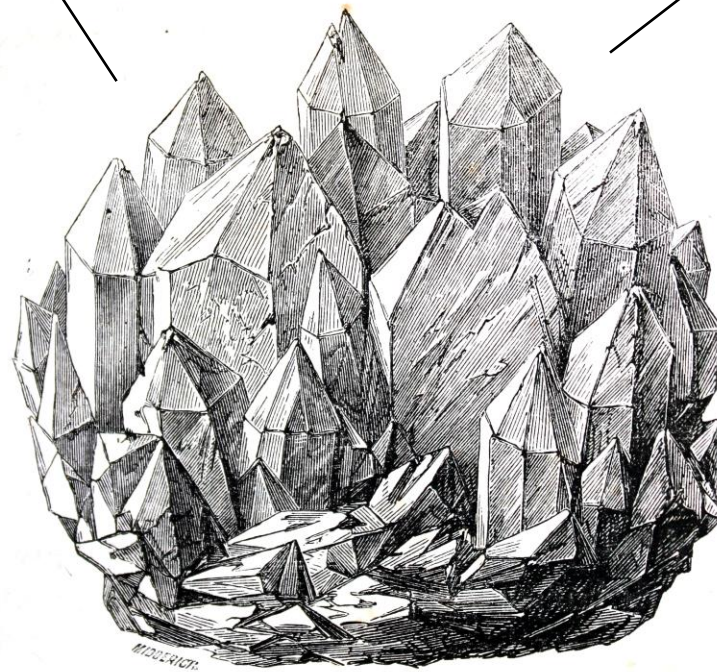
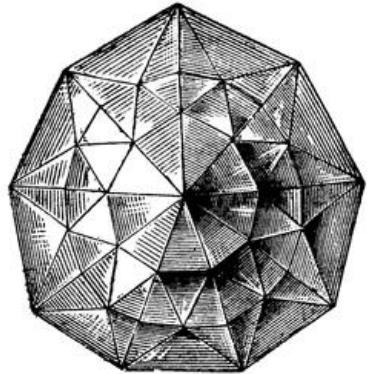


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

+**Intimate** and profound knowledge of the patient, including before illness
Knows the patient's life, history, and values
- The discourse, attitude, and choices of a sick person may change / the caregiver's "fights" may differ from those of the patient.

+Extensive practical and **empirical experience** of the disease
Often provides useful tips and insights
- They are experts in one patient, not necessarily in the disease itself / resistance to change / what works at one moment may not work later / need to see the long term

+**Emotional support** often unconditional
Reduces patient distress and anxiety
- Often neglects their own well-being, becomes socially isolated, has difficulty letting go frustration..



Conclusion
& recommendations

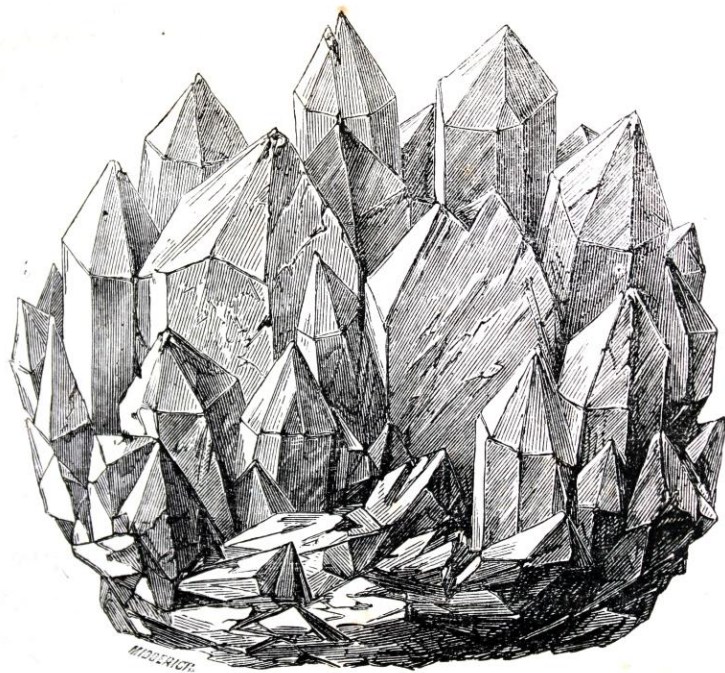
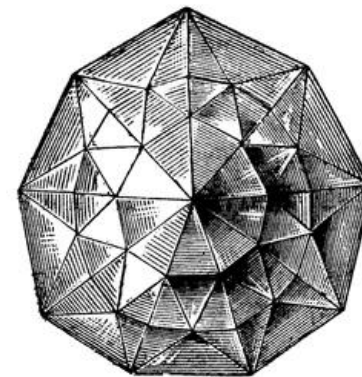


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

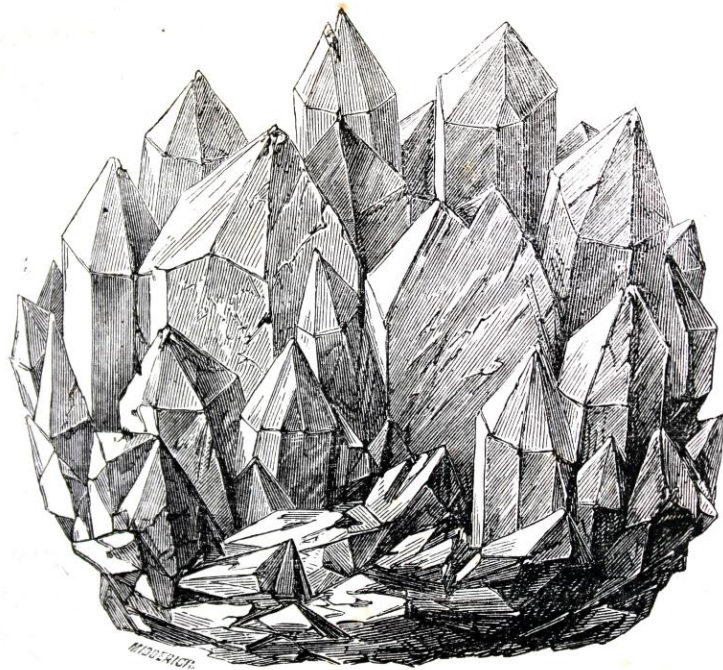
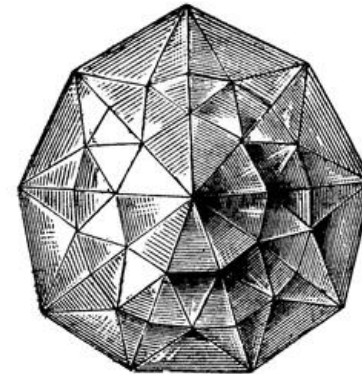


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



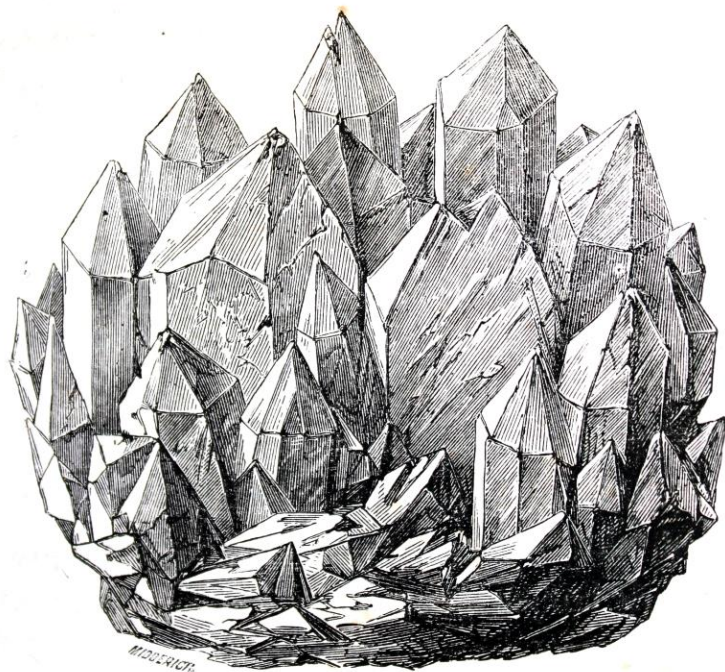
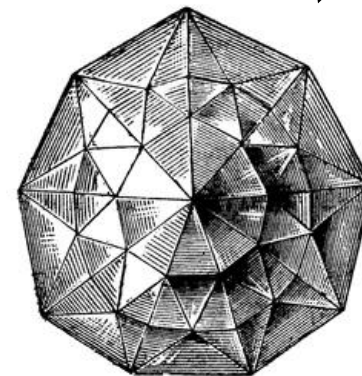


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

Limit hassles and “**secondary worries**”
(administrative problems, unnecessary
paperwork, financial anxieties) lack of
resources...
→ *Focus on the patient and reduce mental
burden*



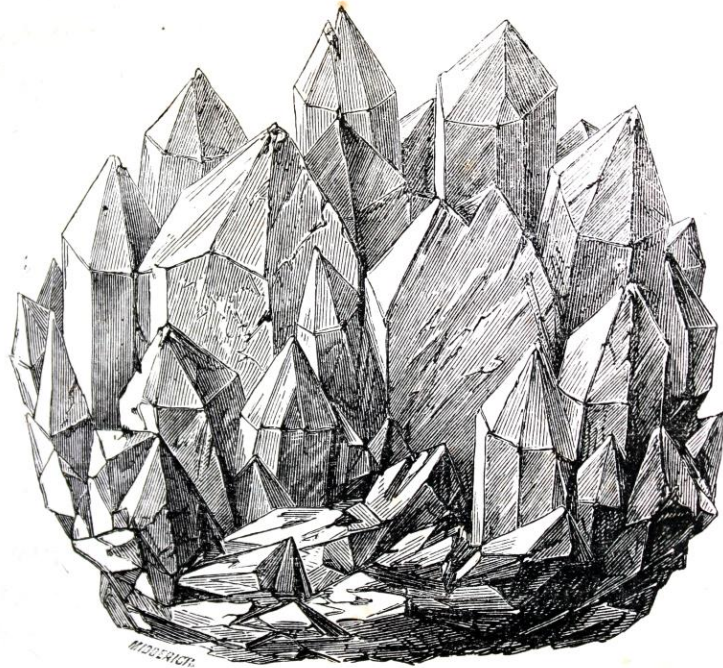


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Offer **TIME** | Start **EARLY**

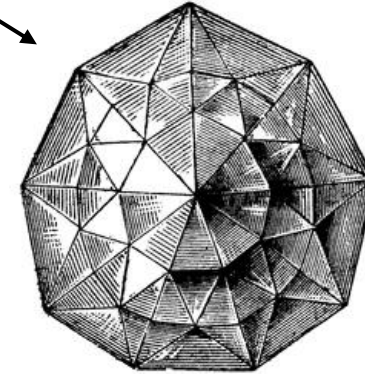
To pause, to do things calmly, for oneself...

To let things settle, to revisit.

Limit hassles and "**secondary worries**"
(administrative problems, unnecessary
paperwork, financial anxieties) lack of
resources...

→ *Focus on the patient and reduce mental
burden*

Grasping the **Challenges**



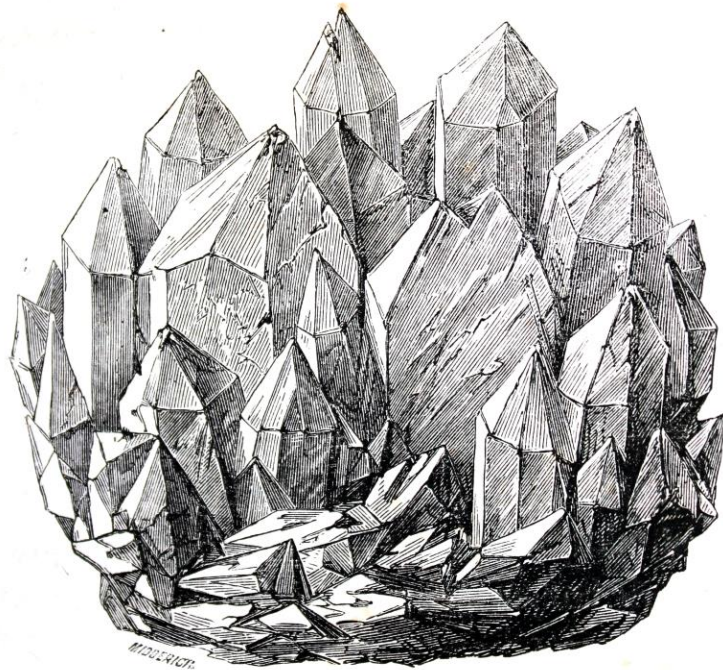


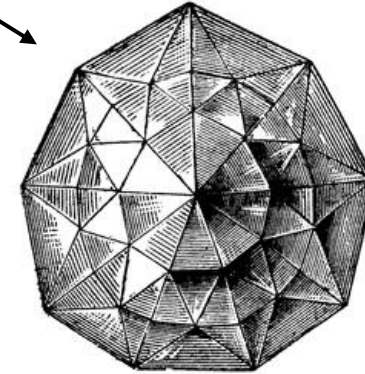
Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

Limit hassles and “**secondary worries**”
(administrative problems, unnecessary
paperwork, financial anxieties) lack of
resources...
→ *Focus on the patient and reduce mental
burden*

Grasping the **Challenges**

6 = 9



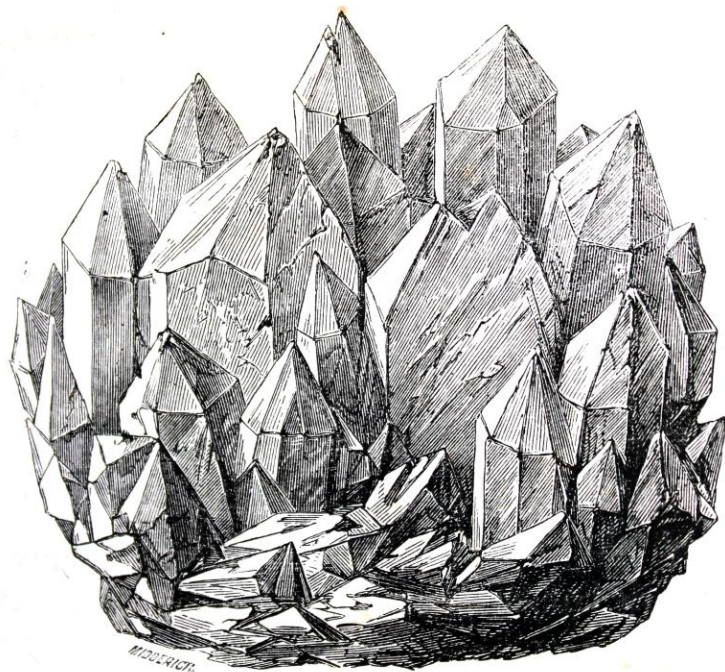


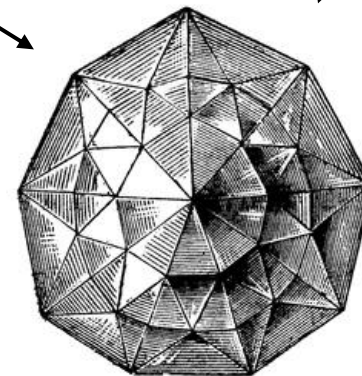
Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

Limit hassles and "**secondary worries**"
(administrative problems, unnecessary
paperwork, financial anxieties) lack of
resources...
→ *Focus on the patient and reduce mental
burden*

Grasping the **Challenges**

6 = 9



Support groups,
discussion groups, training.

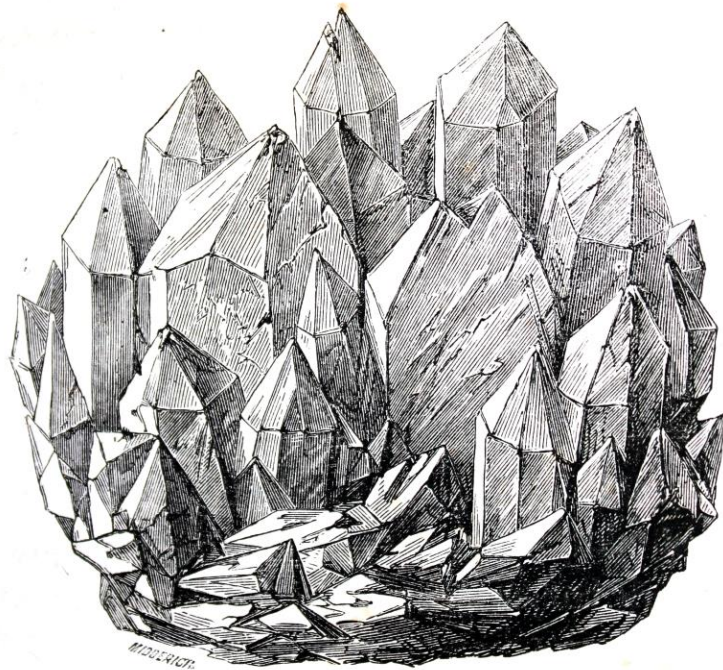


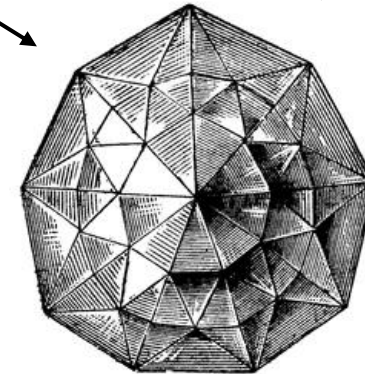
Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

Limit hassles and "**secondary worries**"
(administrative problems, unnecessary
paperwork, financial anxieties) lack of
resources...
→ *Focus on the patient and reduce mental
burden*

Grasping the **Challenges**

6 = 9



Do not place the
WEIGHT OF DECISION-MAKING
on the family/caregivers.

Support groups
discussion groups, training.

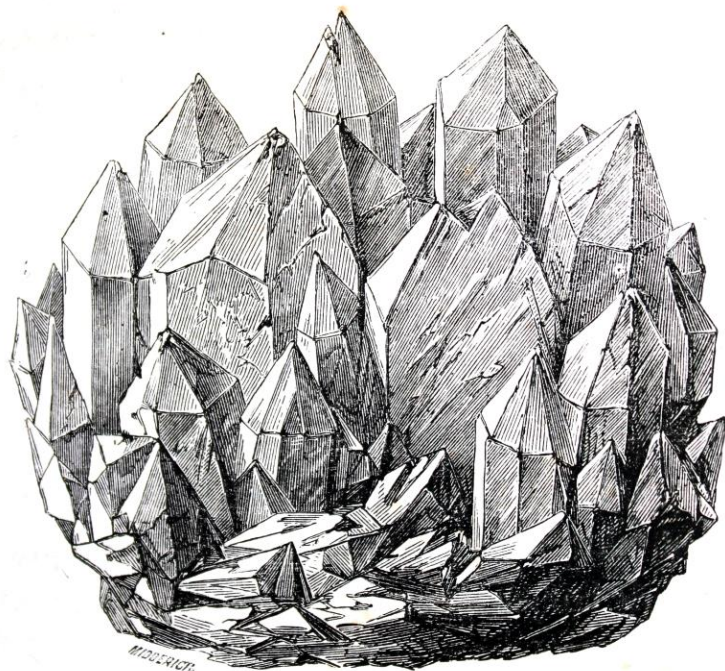


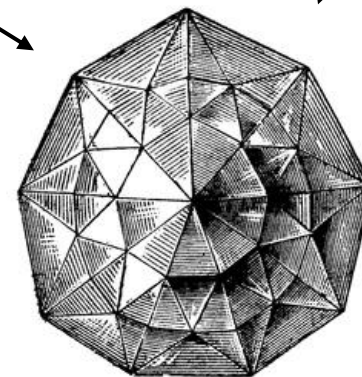
Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

Limit hassles and "**secondary worries**"
(administrative problems, unnecessary
paperwork, financial anxieties) lack of
resources...
→ *Focus on the patient and reduce mental
burden*

Grasping the **Challenges**

6 = 9



Do not place the
WEIGHT OF DECISION-MAKING
on the family/caregivers.

Support groups
discussion groups, training.

Do not judge.

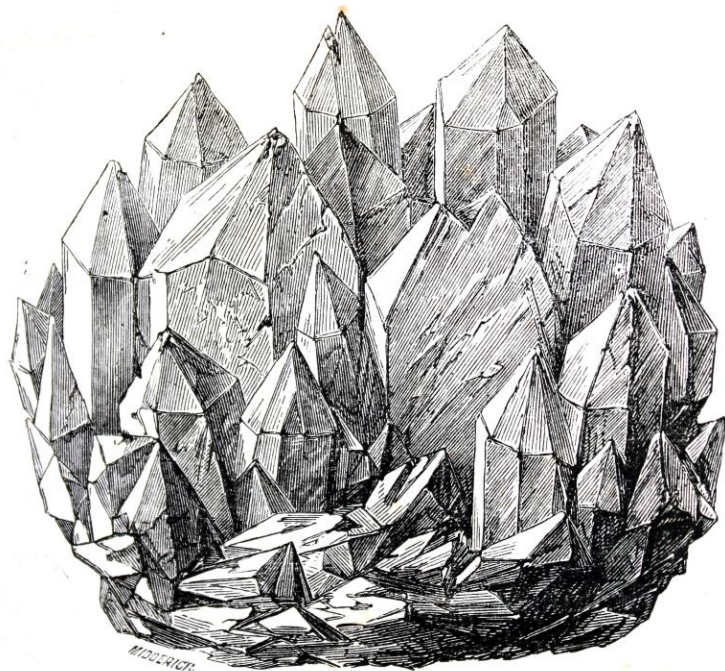


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

Limit hassles and "**secondary worries**"
 (administrative problems, unnecessary
 paperwork, financial anxieties) lack of
 resources...
 → *Focus on the patient and reduce mental
 burden*

Grasping the **Challenges**

COMMUNICATE

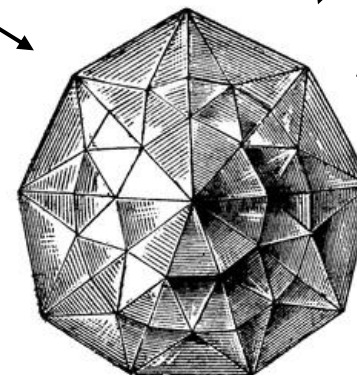
As much as possible,
 on as many topics as possible,
 with as many people as possible

6 = 9

Do not place the
WEIGHT OF DECISION-MAKING
 on the family/caregivers.

Support groups,
 discussion groups, training.

Do not judge.



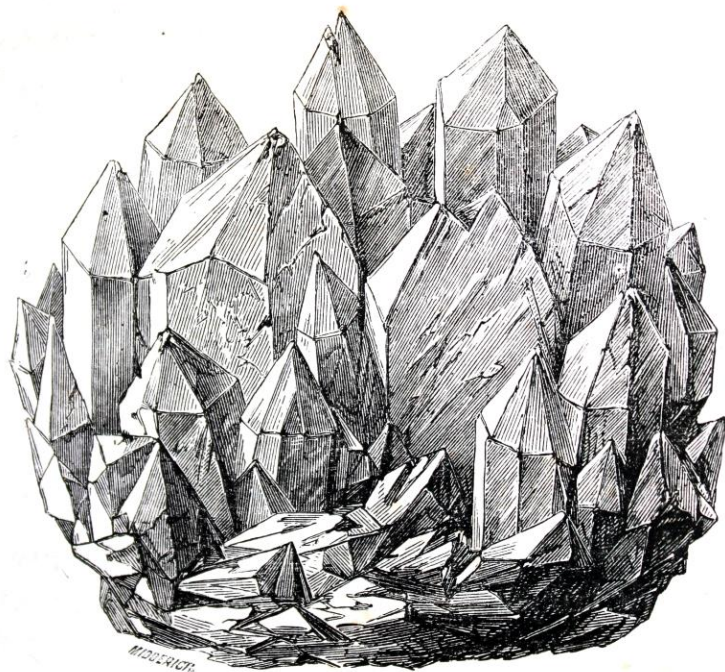


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Grasping the **Challenges**

Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

Limit hassles and "**secondary worries**"
 (administrative problems, unnecessary
 paperwork, financial anxieties) lack of
 resources...
 → *Focus on the patient and reduce mental
 burden*

COMMUNICATE

As much as possible,
 on as many topics as possible,
 with as many people as possible

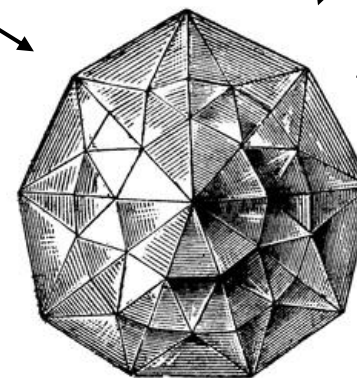
Do not place the
WEIGHT OF DECISION-MAKING
 on the family/caregivers.

Support groups,
 discussion groups, training.

Exchange & communicate about the illness,
 personality changes, acknowledge and **validate**
the subjective experience, help relieve guilt.

Do not judge.

6 = 9



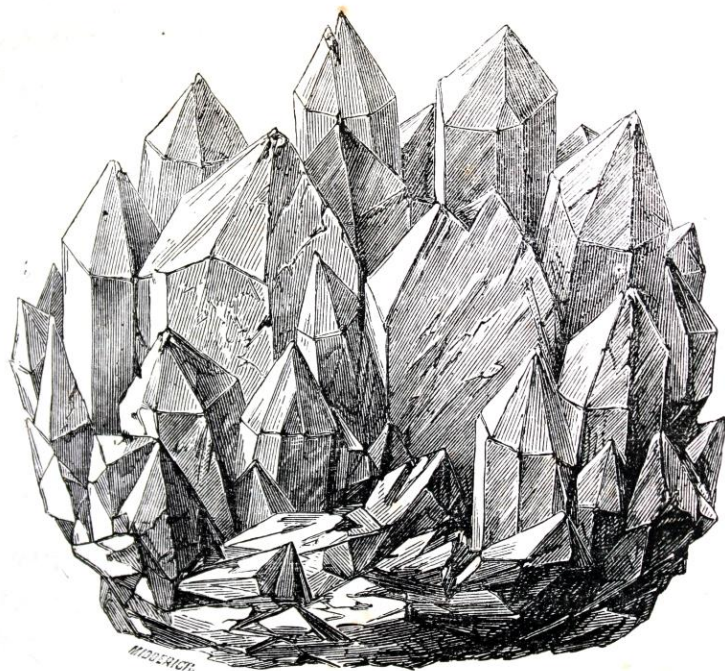


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Grasping the **Challenges**

Offer **TIME** | Start **EARLY**
To pause, to do things calmly, for oneself...
To let things settle, to revisit.

Limit hassles and "**secondary worries**"
 (administrative problems, unnecessary
 paperwork, financial anxieties) lack of
 resources...
 → *Focus on the patient and reduce mental
 burden*

COMMUNICATE

As much as possible,
 on as many topics as possible,
 with as many people as possible

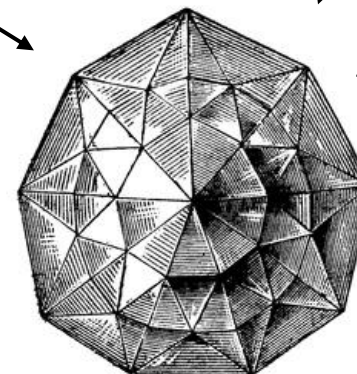
Do not place the
WEIGHT OF DECISION-MAKING
 on the family/caregivers.

Support groups,
 discussion groups, training.

Exchange & communicate about the illness,
 personality changes, acknowledge and **validate**
the subjective experience, help relieve guilt.

Do not judge.

6 = 9



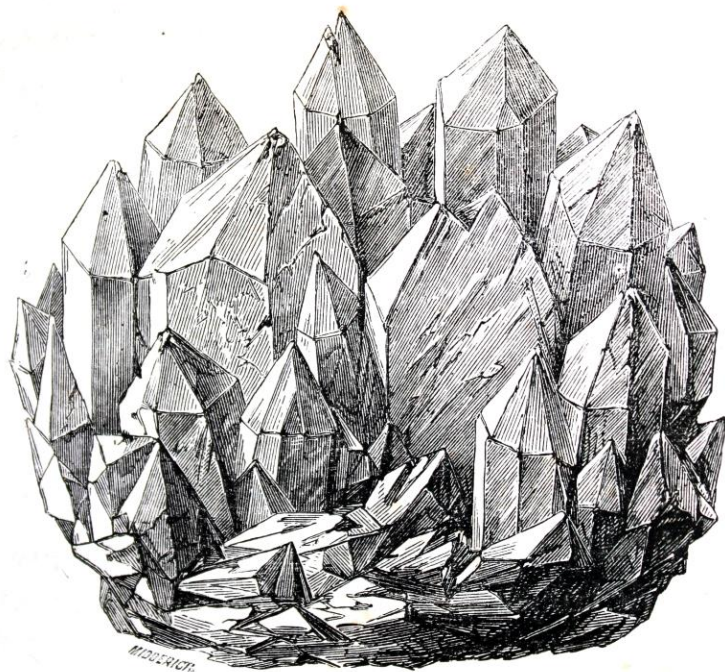
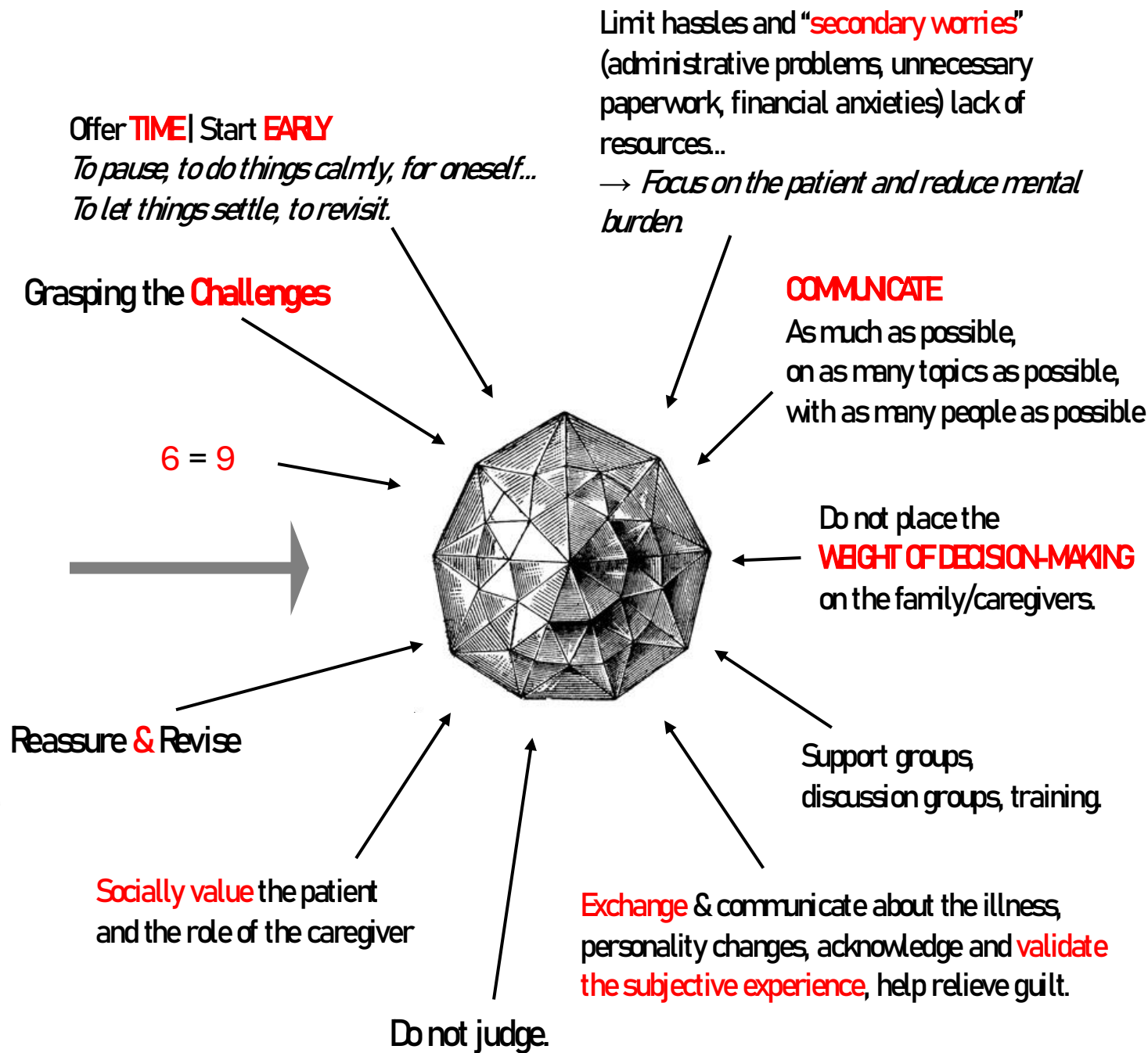


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



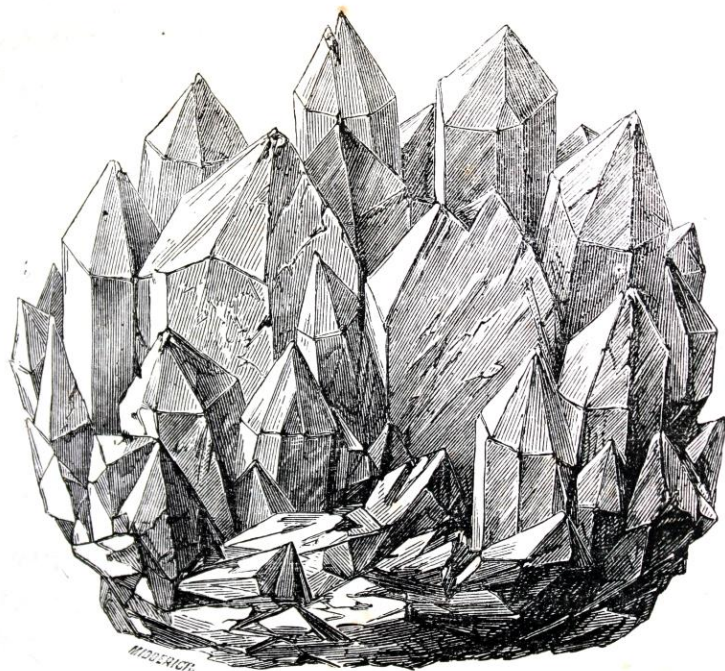
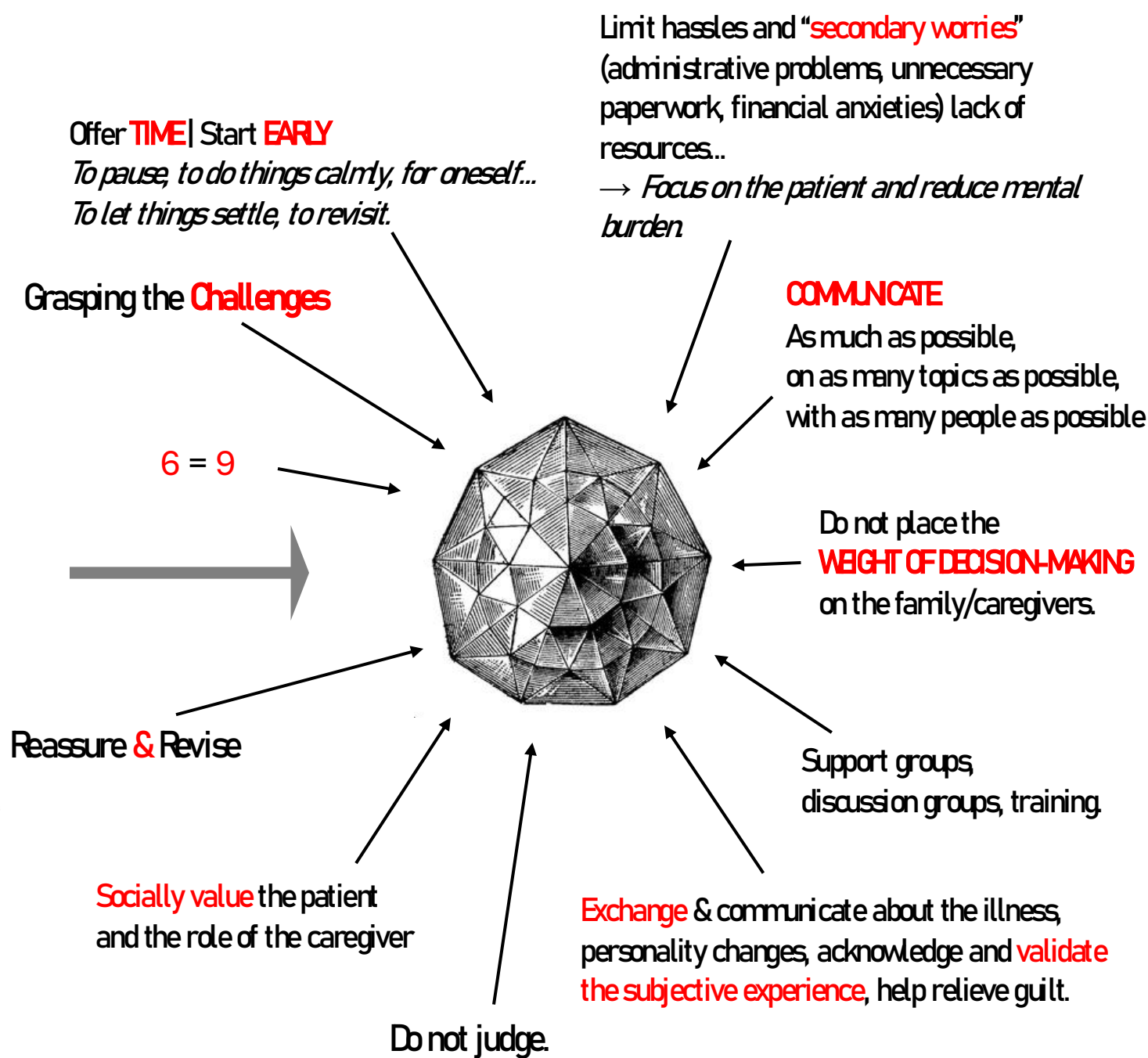


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

There are no “**difficult**” questions.. only silences



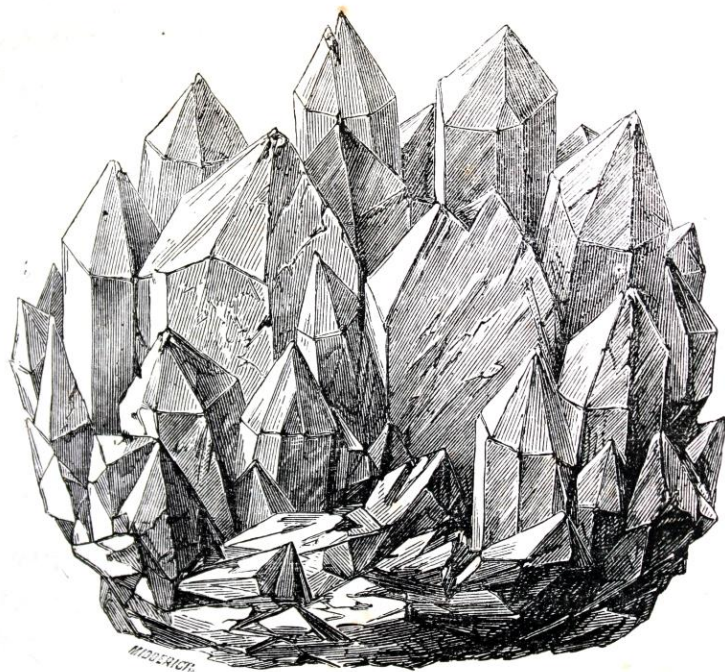
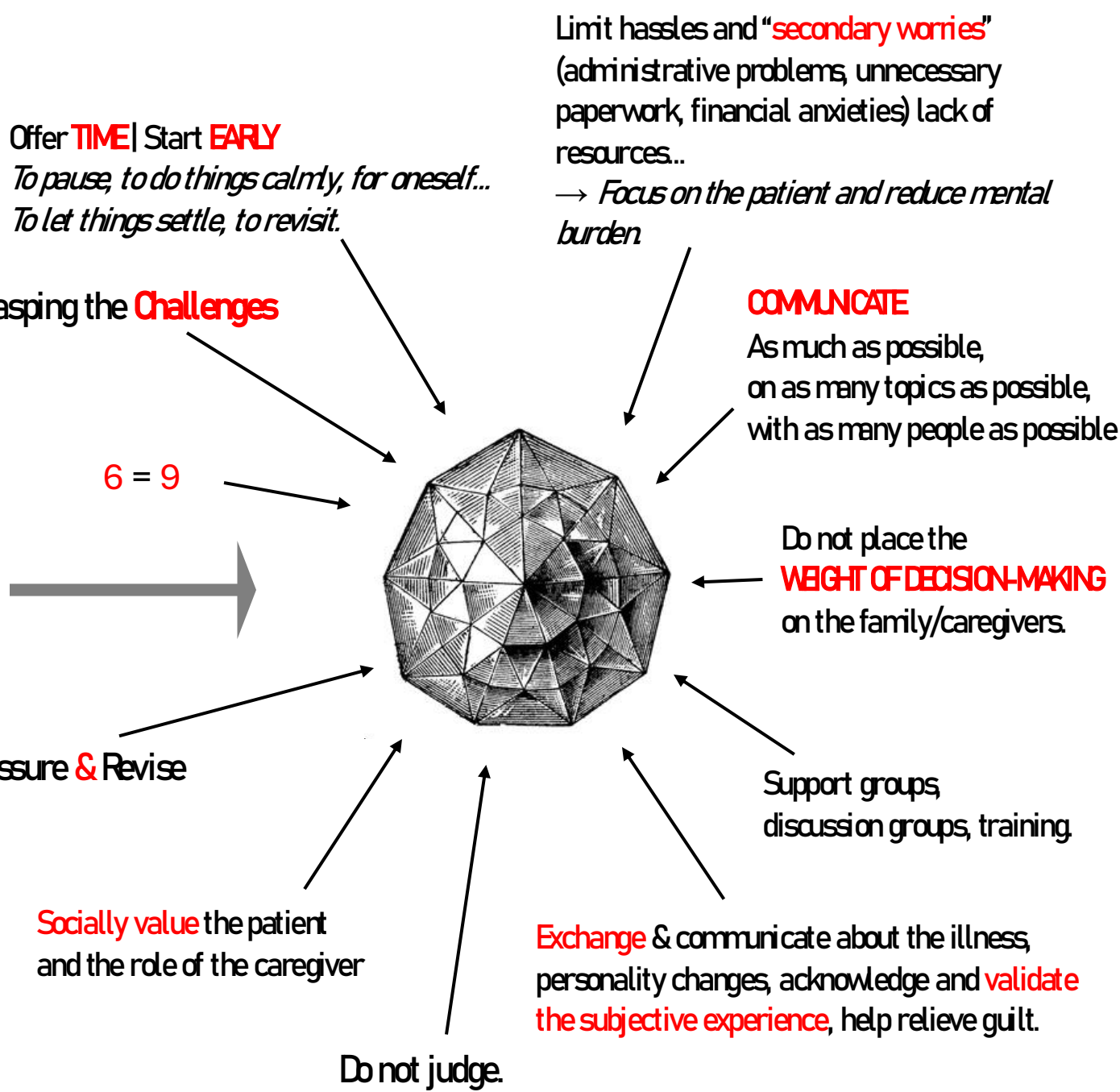


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

There are no “difficult” questions.. only silences



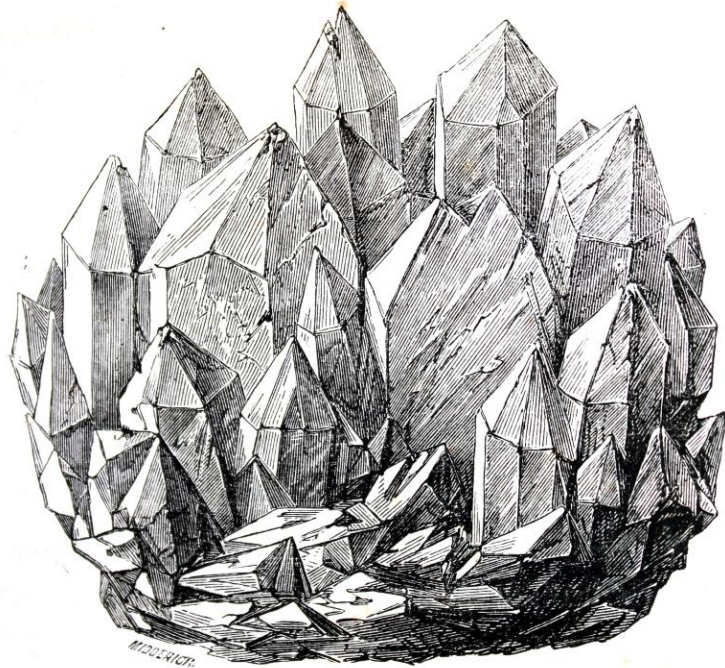
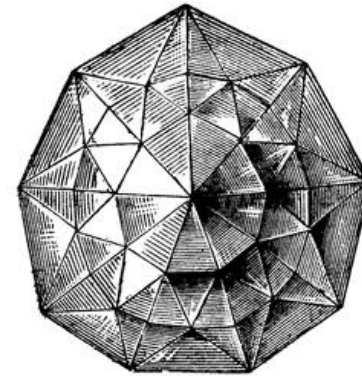


Fig. 15. — Cristal de roche, ou silice pure cristallisée.



There is **NO** *one-size-fits-all* solution!

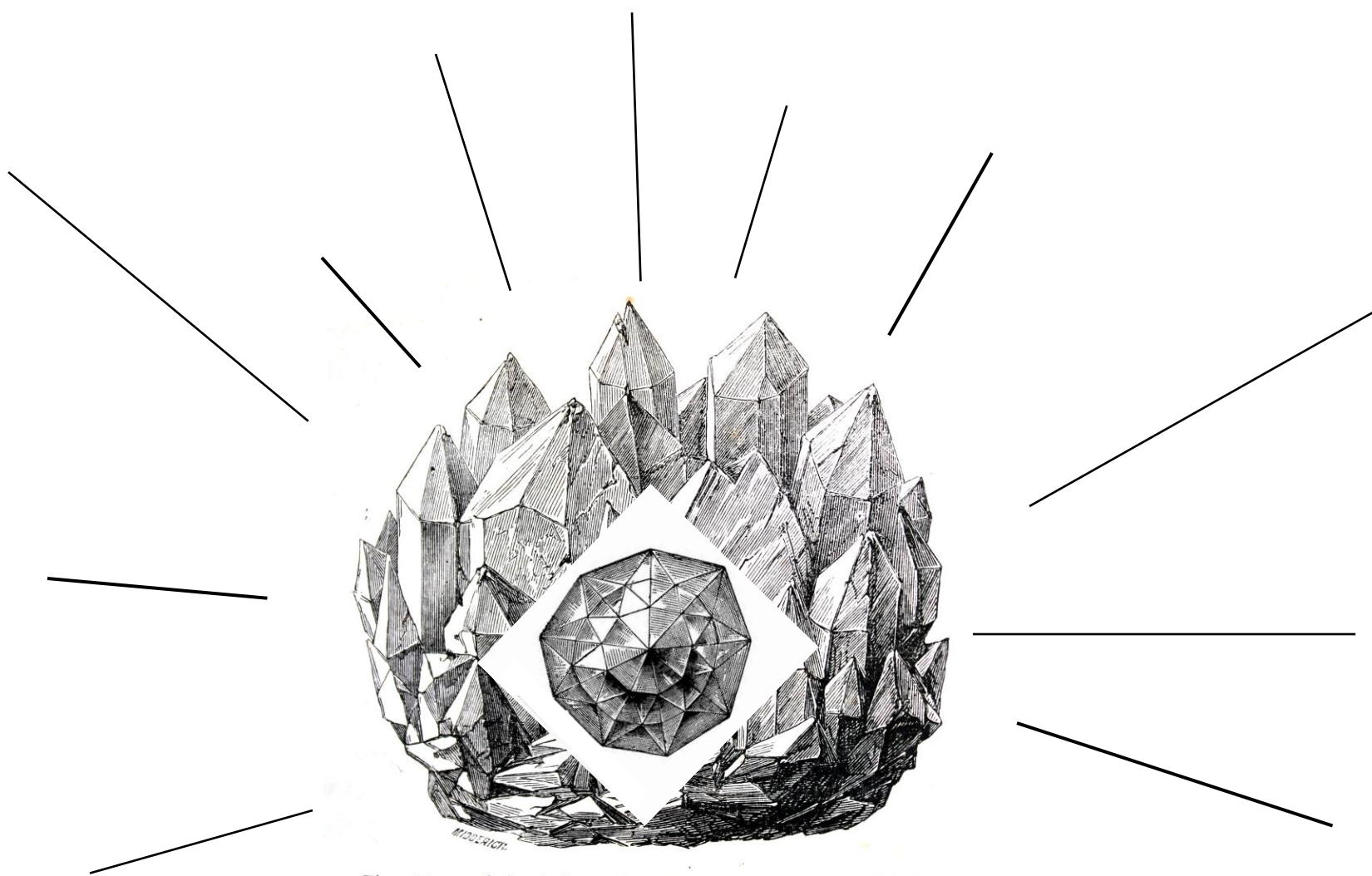


Fig. 15. — Cristal de roche, ou silice pure cristallisée.

Question time

Merci de votre attention | ご清聴ありがとうございました | 9★🦅🧑 | Thank you for your attention