

The
Psychological
Burden
of Living with
Hyperinsulinism

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Intense therapy regimen
(tube care, pump manipulation, blood glucose measurement, cooking,...)

Anxiety of family and friends
(sleep-overs, birthday partys, ...), excluded from
“normal life”

Restricted freedom of movement, every step has to be thought through and organized in advanced
(hospitals, specialists, spare time...)

Not having time to spend with friends



Feeding is everything it is all about



**Good Morning
Let the
Stress
Begin...**

A close-up illustration of a woman's face with red hair styled in a classic 1950s fashion, looking upwards and to the right with a slight smile. She is wearing a blue and white checkered top.

Psychological
adjustment to
chronic
disease
(Stanton et al
2007)

Adjustment to chronic disease
related to:

- Socioeconomic Status
- Culture and Ethnicity
- Gender-Related Processes
- Social Resources and
Interpersonal Support
- Personality Attributes
- Cognitive Appraisal
Processes Coping
Processes

struggling with feelings like:
sadness, fear, jealousy, anger,
helplessness
and the questions why?

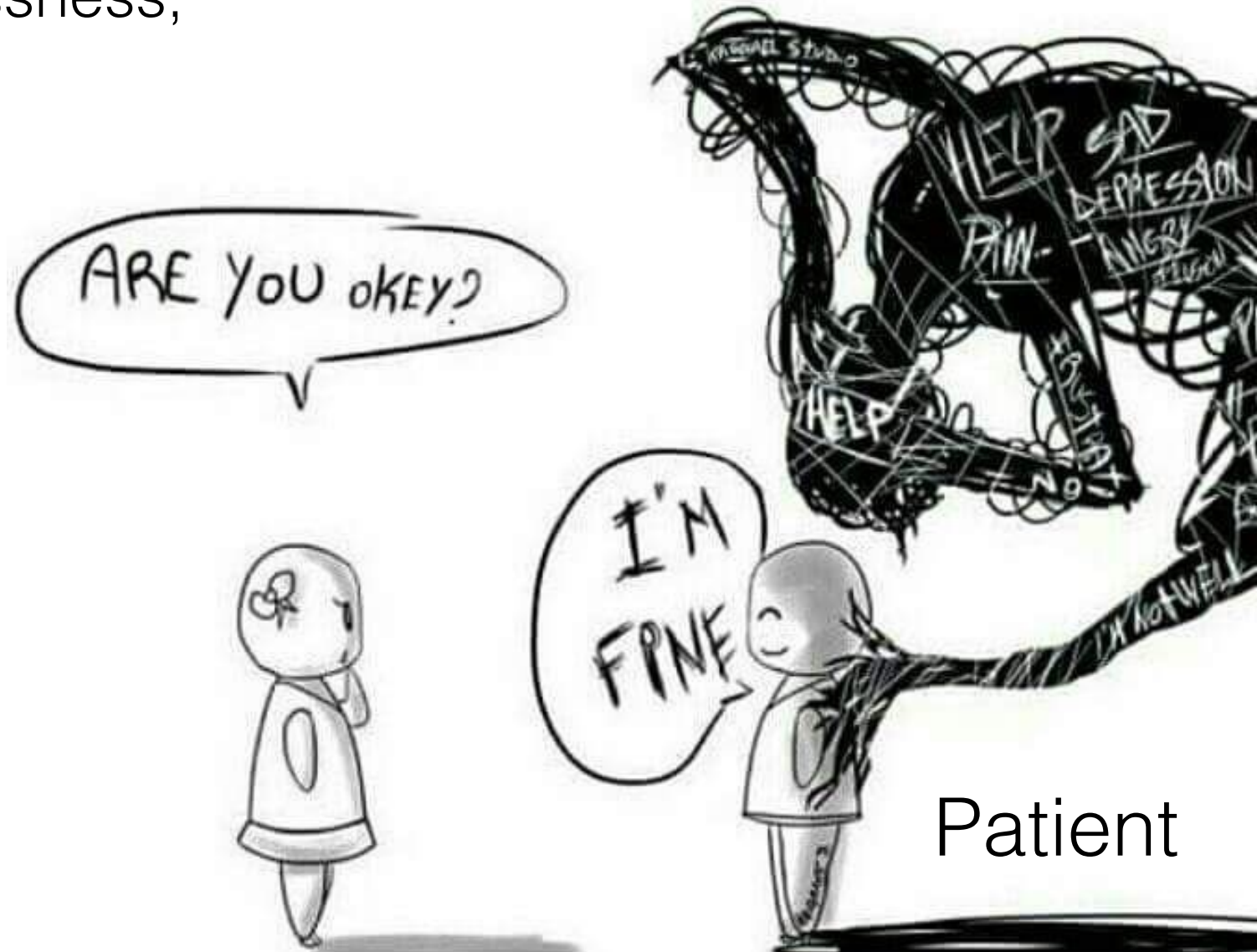
Fear of brain
damage

A virus could be
lifethreatening



Feelings such as fear, anxiety,
uncertainty, helplessness,
hopelessness

Doctor



Patient

Burden on caregivers in various chronic diseases:

Most caregivers report

- moderate depressive symptoms and
- mild to moderate anxiety symptoms.
- social and financial burden on families

Social, Psychological and Financial Burden on Caregivers of Children with Chronic Illness (Khanna et al. 2015)

Emotional
dimensions
of chronic
disease (Turner
and Kelly 2000)

- The emotional dimensions of chronic conditions are often overlooked when medical care is considered
- Doctors may be well equipped for the biomedical aspects of care but not for the challenges of understanding the psychological, social, and cultural dimensions of illness and health
- It can be difficult to diagnose depression in the medically ill but diagnosis and treatment are essential

Participation
can be hard
even not
possible

Sports, swimming
class, hikes,
attending theatre
performances –
challenging!

Anxiety of friends and
parents
(sleep-overs, birthday
partys, ...), excluded
from “normal life”





kindergarden,
school,
institutions

Schools, at least in Austria, are
not well prepared for dealing
with students with a chronic
condition.

(Fichtenbauer 2015)

Education/Job
is a challenge,
especially for
mothers

No time for
relationship, stress
with partner, single
parent



Psychosocial factors related with caregiver burden among families (Toledano-Toledano & Domínguez-Guedea 2019)

- Risk for higher burden:
sociocultural historical premises, many stressors, anxiety
- Protective factors:
upper secondary education, social support networks, family support, family functioning and well-being.

Challenge to deal with authorities and application forms to cope with ignorance or trivialisation

Annoying discussions from responsible authorities regarding care allowance, etc..



Primary Care
Supports for
Children with
Chronic Health
Conditions:
Identifying and
Predicting Unmet
Family Needs (Farmer
et al 2004)

- The most frequent area of need was for information about services and ways to promote child health and development.

A good news:
recent research
indicates:

The impact of looking
after children who live
with complex chronic
conditions is a growing
public health issue.

(Toledano-Toledano 2019)



For now — think of:
Seeking professional help
Joining support groups and seeking help
from advocacy organizations.
Training family members and friends.
Letting them help
making time for self and relationships,
reading and hobbies
Allowing ourselves to be good enough
parents.
Creating a pathway back to work or a
new kind of work
Allowing to feel joy

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