

# Newsletter

## to Health Professionals

Number 2

### Edito

The medical and Health professionals council of three associations, AFAF (Friedreich's ataxia), CSC (cerebellar degeneration) and ASL (spastic paraplegia), recommend a multidisciplinary approach to treating patients with cerebellar ataxia and spastic paraparesia. This second issue of our Newsletter is devoted to psychological follow-up. As in any progressive pathology, psychological care is recommended **for the patients themselves, their close family** (wife, parents, children) and **other people likely** to present an endogenous form of the disease.

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### Psychological follow-up

Recommendations from experts in the field of Ataxias and Cerebellar or Spinocerebellar Degeneration by the medical and allied professions council of the AFAF, CSC and ASL associations

## Frequently asked questions...



### 1 Why is counselling necessary?

- a) To allow patients to **talk** to someone outside the family at any time during their illness about their psychological suffering which is often repressed or hidden from people in their family circle, in order to protect them.
- b) To **prevent** psychological disorders, particularly depression, which is more frequent than in the population at large.
- c) To **treat** these disorders when they appear.

### 2 What is psychotherapy?

Psychotherapy provides people **with a time and space to tell their story**, and be listened to. It consists of talking sessions during which they talk about what they feel, and with the help of the psychotherapist, explore the reasons for their suffering. It is a space bound by professional secrecy in which they can "drop their burden", **speak freely, without judgment and at their own pace**, about what seems to them to be insurmountable. Psychotherapy can be practised **individually, in couples, and in groups**.

### 3 Why does consulting a psychotherapist seem so difficult?

It is not easy to ask for psychological help, nor to suggest it, because of all the prejudices that surround it.

- a) « **I'm not crazy!** »  
Rappelons d'abord **qu'on ne va pas voir un psychologue « parce qu'on est fou »**, comme on l'entend souvent. On va consulter lorsqu'on se sent en difficulté, envahi de sentiments contradictoires, de tristesse, de culpabilité, de peur...  
Lorsqu'on se sent dans une impasse. Par exemple : à l'annonce du diagnostic, au moment du passage au fauteuil roulant, et tout au long de la maladie.

- b) « **It's easier to talk to my close family and friends** »  
... Yes, but **they are not always in the best position to listen to your anxieties**, particularly when they are battling with their own and particularly since you naturally and spontaneously censure your words and feelings to protect the people around you.



**c) « I don't need help ... and it won't change anything »**

Patients sometimes see their encounter with a psychotherapist as a defeat, the sign of their incapacity to pull through by themselves. **But recognising that you need help is a sign of strength both in the present and future.**

**d) « I'm suffering ... and so is my family »**

When someone is ill, the whole family suffers: fear, guilt and powerlessness are natural reactions, but their effects need to be checked when they become invasive. In this case, seeing a psychologist can quickly forestall further problems. It is therefore important to remind the patient's parents and their brothers and sisters that they are entitled to psychological help. **If we want to look after others, we have to look after ourselves first.**

**4 How to suggest counselling**

- Play down the idea of counselling as much as possible.
- Remind the patient how useful it is to talk about their suffering to someone outside the family.
- Tell them that counselling can change the way they see their illness, so that they are neither "for" or "against" it, but go "with" it.
- Tell them that they can see a psychologist (even just once) in times of crisis or during especially difficult periods (before an operation, when they have to starting using a wheelchair, after a break-up).

**5 Who can they consult?**

• A list of psychologists can be found on <http://cpcn1.free.fr/annuaire.htm>

• Genetics consultations include a psychologist in most hospitals. An appointment with a psychologist is often proposed after a medical consultation. This appointment is automatic when a request is made for a pre-symptomatic or prenatal genetic test.

- Multidisciplinary consultations for the treatment of patients with cerebellar ataxia or spastic paraparesis also include an appointment with a psychologist.
- It is often useful for the psychologist to be in contact with the other carers to make treatment as beneficial as possible.

	Who?	Where?	Payment?	Type of practice
Psychiatrist	Physician	- Private practice - State-run counselling centre - Hospital	Always reimbursed by social security (except if more than the statutory fee is charged, which is frequently the case)	- Drug prescription - Psychotherapy - Hospital
Psychologue clinicien	University training in psychology	- Private practice - State-run counselling centre - Hospital	Not reimbursed in private practice	- Psychotherapy - Coaching - Assessment/tests
Psychoanalyst	Psychoanalysis training	- Private practice - State-run counselling centre	Not reimbursed in private practice	- Psychoanalysis

Written by the Medical and Allied Profession Council of AFAF, ASL and CSC.

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