

Forum des associations et dispositifs : un outil de communication de la filière des personnes cérébro-lésées

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Mots clés : Créer du lien ; Informer ; Réinsérer ; Prévenir ; Réseau de soin ; Suivi

Objectifs.– Le pôle de rééducation neurologique d'Aunay sur Odon (Basse-Normandie) propose depuis 2007, un forum des associations et dispositifs en faveur des personnes cérébro-lésées. Il réunit régulièrement, patients, familles, professionnels et bénévoles de cette filière. Les objectifs sont de créer du lien, de partager l'information sur les séquelles spécifiques, de favoriser la réinsertion socioprofessionnelle et d'œuvrer pour la prévention.

Patients et méthodes.– Quarante invitations ont été adressées pour :

- échanger entre professionnels et bénévoles ;
- tenir un stand d'information pour les visiteurs ;
- participer à un débat sur « L'aide aux aidants ».

Deux questionnaires de satisfaction (exposant/visiteur), évaluant les modalités d'organisation, la pertinence des manifestations et plus globalement l'intérêt du forum, ont été distribués.

Résultats.– Seize associations (AFTC 14/50, La Bacouette, France AVC Normandie, La cordée, Handi'cap citoyen, Handichiens) et dispositifs (UEROS, Samsah 14, APF 14/50, Cap Emploi 14, MAS 14/50, MDPH 14, Foyer APF) ont répondu positivement. Aunay sur Odon présentait un stand Rééducation (posters des séquelles cognitivo-comportementales et langagières, vidéo des pratiques rééducatives) et un stand Prévention (tabacologue, alcoologue, diététicienne, kinésithérapeute). Étaient présents avocats, médecins experts, psychiatre.

Environ 300 personnes ont été réunies. Les questionnaires feront l'objet d'une analyse critique détaillée, le degré de satisfaction globale étant élevé tant pour les exposants que pour les visiteurs.

Discussion.– Ce forum nous semble pertinent dans le cadre des missions dévolues aux unités de MPR dans la circulaire ministérielle du 18 juin 2004 : articulation des dispositifs de suivi médical, médico-social et social, accompagnement au long cours du patient et de son entourage, appui sur le milieu associatif, prise en compte des possibilités juridiques de réparation. . .

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Specific multidisciplinary consultation: Adapted physical activity and multiple sclerosis

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Keywords: Multiple sclerosis; Quality of life; Adapted physical activity

Multiple sclerosis (MS) does not prohibit adapted physical activity. Moreover, it has been established that quality of life level of MS people is correlated with physical activity level [1–2].

Objective.– Assessing impact of multidisciplinary consultation on physical activity resumption in MS people.

Method.– A semi-structured telephone questionnaire was administered to 132 patients who attended a consultation before (March 2008–August 2010). Questionnaire incorporated causes and time of activity cessation, feeling of practical difficulties and consequences of meeting with multidisciplinary team. A descriptive analysis was performed.

Results.– Seventy-eight patients responded (age: 47.9 years ± 9.9; duration of illness: 12.9 years ± 7.7; median EDSS: 5.5). Seventy percent of patients were engaged in physical activity at diagnosis. 46.3% of patients stopped at diagnosis announce. After consultation, 68.4% of those who had stopped activity had resumed. In 30% who did not practice, 54% had started a regular activity. Some

(well-being and physical fitness).

Discussion.– Fear of illness and fatigue worsening can explain the physical activity cessation. Even adapted practice is difficult because of symptoms but also by unreachable goals, low level of information on this subject, other people giving advice and underestimation of abilities.

Conclusion.– Exercise impact on people with MS and positive development (physical and mental) after consultation reinforces the idea that specific consultation is required to accompany the patient's project.

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PrEduSED: Patient Education Program for rare diseases, Ehlers-Danlos syndrome

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Keywords: Ehlers-Danlos syndrome; Patient education

PrEduSED is the first Patient Education Program dedicated to Ehlers Danlos syndrome (EDS) patients.

Our aim is to give patients the knowledge and skills based on the stage of their illness, personal knowledge, experience, and capabilities. The program was developed according to the recommendations of the Haute Autorité de Santé (HAS), and an application for approval is to be submitted to the Agence Régionale de Santé Rhône-Alpes.

The program involves two stages:

- three “train-the-future-trainer” sessions (January, February and April 2011: 6 days altogether), followed by the designing of the program itself;
- the implementation of the program.

Sessions are open to all patients with EDS (hypermobile type, diagnosis confirmed by a reference/competence center or a registered geneticist), and are limited to six people, with or without a relative. They attend the same workshops, except for one workshop designed for relatives. Priority is given to patients living far from rehabilitation facilities.

Sessions will be held in Lyon, on our premises (Friday morning to Sunday afternoon). The program will begin with an interview, resulting in an “educational diagnosis”, from which individual educational objectives will be drafted. The program will switch from theory to practice interventions and meetings between participants. The issues will include: the disease, its transmission, diagnosis, medical or additional treatment, as well as therapeutic aids, pain treatment, quality of life, impact on family/caregivers, and how to cope.

Our program is no medical consultation, no “information-only” approach, nor a “from scholarly to unknowing” teaching relationship, but instead we aim to provide a collaborative approach, tailored to the needs and capacities of each patient.

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