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Cognitive and emotional support for the family of a person with frontotemporal degeneration – with particular consideration given to a minor

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Summary

The diagnosis of frontotemporal degeneration changes the entire family, being an unexpected and emotionally burdening experience for all the individuals in the family. Confrontation with problems that are diametrically different from those that occur in the family system without a person with a major neurocognitive disorder requires the development of new coping strategies. If these coping mechanisms are to be useful, they should undergo successive modifications that consider the progression of the neurodegenerative disease and the dynamics of the family system. Providing information on different aspects of this group of diseases is the basic form of supporting families with frontotemporal degeneration.

Growing up in a family with a parent affected by frontotemporal degeneration is a crucial, though non-normative, developmental experience of a child. It results in an irreversible loss of the existing relationship and the necessity to form another relationship with the affected parent. The paper focuses on providing support for a minor. Graphic medicine can be a support tool, which combines verbal communication with graphics, and, as a result, it provides knowledge on health problems and also creates the possibility of expressing emotions triggered by the presence of the disease in the family.

Keywords: frontotemporal degeneration, caregivers, graphic medicine

Problems of relatives of the person with frontotemporal degeneration

Major neurocognitive disorder (MND; the term used in the Diagnostic and Statistical Manual of Mental Disorders DSM-5 [1], replacing *dementia*) is rather expected in the elderly. The diagnosis of MND at an earlier stage of life is an experience that

is significantly different from the normal human lifespan. The diagnosis of a neurodegenerative disease in a person under 65 years of age (especially before the age of 30) is usually a very surprising experience for affected individuals and their relatives that disorganizes the functioning of each person and the whole family system [2, 3].

In the literature, the problems of families due to a neurodegenerative disease were primarily reported in relation to the elderly with Alzheimer's disease (AD) and adults acting as their family caregivers, mostly a partner aged over 65 years or an adult child of the affected person. Considerably less attention was paid to the problems of minors whose parents are diagnosed with a neurodegenerative disease [4]. However, there has been an increasing interest in research on the functioning of families with a person with early-onset dementia (EOD; *young-onset dementia*, YOD), i.e., showing the symptoms of the neurodegenerative disease below the age of 65 [5, 6].

This category applies to frontotemporal degeneration (FTD), which usually occurs in the 5th decade of life [7]. However, the catalog of medical conditions with YOD goes beyond this group of diseases. Problems of families struggling with YOD are not identical to the problems of families in which the person has late-onset dementia (LOD) when the symptoms of the neurodegenerative disease occur over 65 years of age. This difference is mainly due to the fact that a person with YOD with the early developing MND can be a parent of a minor [5]. It is reported that every fourth person with YOD has at least one child under 18 years of age [8]. The family context is characterized by diversity which is defined e.g., by the age of a child and their developmental stage at the onset, the diagnosis of the parent's disease, the number of children, the presence of the other parent and their involvement in upbringing the offspring and taking care of their partner with YOD. Therefore, children from families with YOD share some common experiences related to the parent's disease. However, some experiences are different, even in the same family [2].

The Association for Frontotemporal Degeneration (AFTD) is involved in studying the problems of families of persons with FTD and providing support to the families in solving problems. According to AFTD [4], the process of family coping with the diagnosis of FTD involves confrontation, mostly by the partner of the affected person, with three fundamental tasks:

(1) to reach the reliable, current and straightforward knowledge related to FTD to plan and provide care for the affected person;
(2) to decide how to address the diagnosis and disease with their children;
(3) to provide support to a child who is in grief due to the changes occurring in the relationship with the parent affected by FTD who loses independence and behaves in a different manner than previously known to the child.
(4) Some families with FTD are confronted with another fundamental problem, i.e., genetic conditioning and the risk of passing the disease to a child – 40% of individuals with FTD have a family history of dementia, and less than 10% have an autosomal dominant pattern of inheritance, which means that offspring have a 50% chance of developing the disease [4, 7].

Based on the research on partners and adult children of individuals with FTD who were under the age of 18 when the symptoms of this disease occurred in a parent, Denny et al. [4] developed a comparison of priority needs from two perspectives, i.e., of a partner of a person with FTD (parent without FTD) and children and adolescents growing up in families with FTD. In this paper, the data from AFTD were completed by the results of studies on families of individuals with YOD, mainly FTD or young-onset AD (YOAD) conducted by Barca et al. [2], Gelman and Rhames [5], Millenaar et al. [6], Johannessen et al. [8, 9] and Nichols et al. [10]. AFTD distinguishes three fundamental areas on which the support of the family should be focused: (1) access to information on FTD; (2) coping with emotions; (3) managing daily living needs [4]. It should be emphasized that currently there is no effective treatment for FTD and individuals die approximately 80 months after the occurrence of the first symptoms, and hence the support for a person with FTD and their relatives is considered a key intervention [11].

1. Obtaining information about FTD

The family of an individual with FTD needs cognitive (informational) support consisting of: (a) an easy access to information on FTD that is multidimensionally related to the neurodegenerative diseases and (b) individualization of general information on FTD to a specific family. Obtaining knowledge creates opportunities to improve the understanding and predicting of changes in the family and the situations of individuals. The need for information applies not only to a partner of a person with FTD and an adult child of the affected parent but also to a minor [4]. Information can also be sought by parents or siblings of the affected person. Effective communication of the content includes the processing capabilities of the recipient that are determined by different developmental stages in terms of cognitive and emotional functioning of children, adolescents and adults. However, a lack of knowledge promotes excessive avoidance of contact with a person with FTD and intra-family conflicts [2, 6, 8, 10].

Table 1 contains a detailed description of the need for information of relatives of a person diagnosed with FTD [2, 4–6, 8–10].

Table 1. **The need for information in a family of a person with FTD**

Partner of a person with FTD (parent without FTD)	Minor of a parent with FTD
Information categories:	
– specificity of the disease: diagnosis, symptoms, rate and course of progression; – what, when, and how much to say to a child about the diagnosis, prognosis and behavior changes of the affected parent; – genetic risk, genetic testing and answering child's questions on the possibility of inheriting the disease; – providing long-term care to the affected partner in the home setting; – taking care of the affected partner with a simultaneous recognition of child's needs; understanding developmental needs of a child; adapting strategies as the child ages over the disease course; – access to the support system for oneself and a child – institutions and the type of support; – coping with the end stage of FTD; accessibility of the nursing home/hospice and bereavement support for a child.	– the disease of a parent is presented in a manner adapted to the developmental stage of children and adolescents in terms of content and form; – it is particularly related to an adolescent with a significant risk of a family disease: genetic risk, genetic testing and life with the risk of developing FTD; – who, what and how much to say to friends, peers and other people about the parent's disease; deciding about the scope of information given to different people, giving clues to help others understand the situation and contact the affected parent; – behavioral symptoms (e.g., following strict patterns of behavior, inactivity, inadequate laughter, insulting others) and practical guidelines for coping with them; – language symptoms (e.g., confusing words, reduced vocabulary, no participation in conversations) and practical clues that facilitate communication with the affected parent; – coping with new symptoms (progression) of the disease and the related in-home and out-of-home situations.

Educational materials that meet the needs of families with FTD contain information given in Table 1. Suggesting sources of updated knowledge on FTD, current and expected family problems and useful coping strategies is one of the tasks of professionals working with the family in the diagnostic and therapeutic process. After being familiarized with the proper knowledge, a parent without FTD will be prepared to talk to a child [4]. Educational brochures in English available free of charge on the website of AFTD are an example of such information transfer for families with FTD [12, 13]. Selected websites are also helpful, particularly the AFTD website in English (https://www.theaftd.org) along with the website for children and adolescents (http://www.aftdkidsandteens.org).

It is difficult to obtain informational support for FTD families in the Polish language. There is a lack of professional educational materials and websites that contain information sought by families. For this reason, bearing in mind the needs of a minor of a parent with FTD, the authors of the paper attached an excerpt of the Polish edition of the children's activity book by Tiffany Chow (behavioral neurologist) and Gail Elliot (dementia specialist) entitled in English "*Frank and Tess – Detectives! A children's activity book about frontotemporal degeneration* (*FTD*)" [14].

The full electronic version of the book in Polish can be obtained free of charge by contacting the co-author of this paper (S.P.).

2. Coping with emotions and FTD

Changes in the functioning of a person from the family that are undiagnosed behavioral and/or language symptoms of FTD, a complex diagnostic process, misdiagnosis before establishing the correct diagnosis and the progression of the neurodegenerative disease trigger intense and varied emotions in relatives. Among them, the following are predominant: surprise, anger, anxiety, sadness, despair, shame and disgust. Children may experience feelings of guilt, blaming themselves for changes that occur in the parent. Establishing a medical diagnosis which determines the significance of these changes can offer some relief [5, 10].

Diagnosing FTD is a difficult task. Due to the nature of FTD, particularly ambiguity of the early stage of behavioral variant FTD (bvFTD), which favors inaccurate interpretations of the family (e.g., midlife crisis, stressful situations) and the medical personnel (e.g., marital conflict, depressive disorder), it takes much more time to establish the diagnosis compared to LOD. Often in the prediagnostic phase the change in behavior of the relative as reported by the family ("they are not themselves") is treated by clinicians as poorly specific or irrelevant, all the more so because the affected person does not generally report complaints of the lack of self-awareness of difficulties typical of FTD, and the results of structural neuroimaging studies and a neuropsychological assessment may reveal only subtle abnormalities [2, 7]. The diagnosis of FTD usually takes 5 years, which is twice as long as the diagnosis of AD and is associated with delayed targeted management of the disease by the family [11].

To protect a parent without FTD from an additional burden, a child may not reveal their own experiences or needs that reflect family destabilization or other non-family-related problems. This can create a false impression of protecting a child from the impact of the parent's disease on the child's emotions. Hence, from the perspective of a parent without FTD, the disease may affect a child to a lesser extent than the real experiencing it by a child. On the other hand, it is the parent without FTD that can seek emotional support in a child, which can be a factor that makes it difficult for a teenager or an adult child to loosen the ties to parents [5, 15].

Blandin and Pepin [11, 16] developed a model of pre-death grief in dementia caregivers, which includes a cycle of three psychological states:

(1) *Separation state*: a series of overlapping losses in a relationship with the affected person (e.g., to handle existing domestic activities, joint plans, communication), leading to an increase in distance and the sense of strangeness; initially, the subtlety of changes makes it difficult for a relative to recognize losses and if they see them, they may deny them.
(2) *Liminal state*: emotionally exhausting experience of ambiguous loss resulting from the separation of psychological and physical loss – a person with MND

is alive, is physically present, but gradually and irreversibly stops behaving in a manner known to the family; the loss of the ability to recognize a relative by the affected person is a particularly difficult experience for the relative [10].

(3) *Re-emergence state*: the caregiver's acceptance of the reality of losses in a relationship with the affected person and the resulting consequences and adaptation to new life circumstances, e.g., learning a different manner of communication and organizing new forms of care.

Table 2 shows areas of particular importance in terms of emotional functioning of relatives of a person with FTD [2, 4–6, 8–10].

Table 2. **The need to cope with emotions in the family of a person with FTD**

Partner of a person with FTD (parent without FTD)	Minor of a parent with FTD
Areas of emotional regulation:	
– the course of FTD; the future of the family: changing symptoms of the disease resulting in changes in the family situation and the need to adapt; – fear for health of a child due to potential genetic risk; – child's experiences, particularly their grief, anger, desire for the disappearance or death of the affected parent; avoiding contact with the affected parent by a child; – an unclear role of the affected person in the family and partner relationship: to what extent can they remain an involved parent and partner; – excessive decision-making related to the family and the excessive responsibility for taking care of the partner and raising a child; – increasing distance, strangeness and loss of intimate relationship with the affected partner; – feeling of alienation and the lack of understanding by others; narrowing and loss of contacts with people outside the family; – the decision to transfer the affected partner under constant care of the care center or hospice: mixed experience of relief and guilt; – death of the partner.	– anxiety about the family (i.e., separation of parents, the condition of the affected parent, illness of the parent without FTD); – blaming oneself for causing family problems; – loss of the previous relationship with the affected parent; a sense of loss of parental love and rejection by the parent who stops showing concern for a child and family; – confusion about taking care of their own parent; – fear of inheriting FTD in older children; – behavioral symptoms of the disease of the parent, unpredictability of behavior e.g., raising the voice to others, taking goods from the store without paying; – shame and embarrassment at the parent's behavior, unwillingness to undertake joint activities, wish for the parent to disappear or die; refraining from inviting friends home; – reactions of people outside the family to symptoms of FTD treated as impolite, strange and aggressive behavior; – expression of experiences (especially anxiety, anger and despair) triggered by the parent's disease in relations with adults; – noticing the burden, increased effort, and emotional tension of a parent without FTD; – underappreciation of the child's involvement in household activities by adults; – spending special occasions, e.g., Mother's/Father's Day, holidays; – death of the affected parent.

Providing emotional support to the family that soothes the intensity of complex emotions triggered by FTD is a part of therapeutic management [4]. Table 2 shows the hotspots of the emotional functioning of the child and the partner of a person with FTD that should be considered in the support process. The lack of interest in a child's thoughts or emotions on the part of adults, the absence of conversations on this subject and decreasing the importance of their experiences may promote chronic complaints of somatic conditions, aggressive behavior, depressive or anxiety symptoms in the child.

3. Coping with daily life matters and FTD

FTD changes the existing pattern of daily functioning of the family in which the need to provide care to the affected person is gradually increasing. A parent with FTD becomes less and less involved in taking caring of a minor who loses parental care despite the fact that they still need it. One of the major changes in families with FTD is related to the reversal of roles in the affected parent-child relationship, i.e., a child begins to look after their own parent. Using the words of children, they become "the parent of the affected parent". A minor who participates in this care adopts the role of a young caregiver. The term *young caregiver* describes a person under 18 years of age who takes care of another person, usually a family member who due to a somatic disease, mental disorder and/or advanced age is not independent [10].

A parent without FTD reorganizes the amount and the way of spending time with a child, performing household activities and participating in activities outside the home setting. In families with FTD, a young caregiver is involved in the care of the affected parent in various ways, which is influenced by the ability of the other parent to function as a primary caregiver. A young caregiver can also take care of younger siblings or become responsible for additional household activities. In addition, a parent without FTD may treat a child, especially a teenager as an advisor when making decisions about family matters, including those concerning the affected parent [5].

Table 3 shows the fundamental changes in everyday life of a partner and a child of a person with FTD that require a special adaptation effort [2, 4–6, 8–10].

Table 3. **The need to cope with daily life matters in the family of a person with FTD**

Partner of a person with FTD (parent without FTD)	Minor of a parent with FTD
Changes in everyday life:	
– change in financial situation – organizing family affairs, including the provision of care to a person with FTD with more limited financial resources than previously available; – searching for FTD-related professionals who can provide the family with professional multidimensional support; – ensuring safety to the partner and increased care for the safety of a child with the progression of the disease: monitoring the potential threat, intervening if necessary; – taking over additional activities in the household, previously performed by the person with FTD; – considering the child's needs related to spending time with their peers and developing their interests apart from involving a child in the household activities; – cooperation with school in supporting a child in pursuing education and maintaining contacts with peers; – providing a child with supportive contact with adults from outside the immediate family, including the same gender as of the affected parent; – coordinating activities: caring activities in relation to the affected partner, spending the time with the child, professional work, and other matters from inside and outside the home.	– extending participation in domestic activities; – taking care of the affected parent and younger siblings; – adapting to changes in the financial situation of the family, limiting the possibility of expenses; – taking up employment by a teenager; – changes in the home space, e.g., protection against wandering of the parent with FTD, control of access to food in the kitchen; – solving issues related to school activities, extracurricular activities, moving outside of the house; – narrowing the scope of relationships with peers in favor of their own family; – seeking support from people who are familiar with FTD, especially from a peer who has a parent with the disease, in the form of Internet contact, individual or group meetings (more frequent situations, i.e., grandfather/grandmother with dementia or a parent with another serious chronic disease such as cancer are not equivalent to a situation in which dementia affects a parent); – answering the questions from other people related to a parent and the disease.

The involvement in a parent's disease makes it difficult for a child to focus on school education, interests and contacts with peers [9, 15]. Excessive responsibility associated with caring and home activities is one of the factors affecting the cognitive pattern of an adolescent. It may reinforce *compulsive caregiving*, i.e., the continuation of excessive caring behaviors also in adulthood toward people from/outside one's own family or a self-sacrifice pattern characterized by an imbalance in the relationships in terms of reciprocity (giving vs. taking) with neglecting one's own needs [10, 17]. If siblings grow up in a family with FTD, the greatest risk of pressure of responsibility applies to the oldest child or to the one who has lived the longest in the family home. Transfer of developmentally inadequate expectations to a child is facilitated by the parent's avoidance of the role of a caregiver of a partner (e.g., expressed by intensive work outside the home), and social isolation of a family with FTD (e.g., rejection of offers of professional care services) [2, 5]. On the other hand, struggling with difficulties based on high quality parenthood and social support available outside the family develops

resilience, i.e., resources to cope with stress and obstacles of everyday life. In turn, resilience facilitates a gradual reaching the stage of acceptance of the occurrence of one's own disease or the disease of a relative [8, 9].

When recognizing the family situation of a child and its consequences, the following should be considered [4]:

(1) the scope of care activities of a child:
   a) taking care of the affected parent: the amount of time spent together and the undertaken activities, e.g., walking, preparing meals, bearing in mind the drug intake schedule, assistance in getting dressed or hygienic activities (which can be particularly emotionally burdening);
   b) b) taking care of younger siblings;
(2) child's household activities, e.g., cleaning, shopping, cooking;
(3) the impact of the role of a young caregiver on the child's functioning, in particular emotional state, exhaustion, relationships with peers, attendance at school, problems with doing homework, aggressive behavior that releases frustration;
(4) family use of an external support network that goes beyond its own structure.

Various authors [2, 4, 8] indicated the need for continuation of studies on the long-term consequences of growing up in a family with YOD and the need for the health care sector to address (mostly overlooked) problems of children from these families. It is also postulated that the support of a family with YOD ought to include multifaceted coordination by one specialist who should prepare a written, periodically revised plan of management. The plan addresses the problems of all people in this family, including each child, and has proposed or implemented interventions [2].

In Poland, the situation of minors in families with YOD and the type and support provided to them are not sufficiently analyzed. For example, there had been no paper related to this issue in the database of the Polish Medical Bibliography (as of July 2021).

Strategies for supporting minors in families with FTD

Based on the studies of families with FTD, recommendations were made for supporting minors who grow up in such families. AFTD distinguishes two types of strategies, i.e., general and family support [4].

General strategies are focused on educating the society in terms of dementia, its different variants, problems and needs of families with a person with dementia, including the specificity of FTD. In the context of YOD, the message shaping awareness of the occurrence of dementia in young persons is crucial. The lack of such awareness promotes the increase in burdens (Tables 2 and 3) which families with FTD struggle with [10]. The basis for creating social awareness that counteracts the stigmatization of the affected person and their family is proper information on FTD, YOD and the phenomenon of adopting the role of a young caregiver by minors. Such information

should be particularly addressed to persons who have professional contact with children and young people, e.g., teachers [2, 4].

In turn, *family support strategies* include three subcategories [4]:

(1) Dialogue with a child, which is adequate to their development needs and consists of [2, 4, 6, 8, 10]:
   a) Informing a child by the relatives about the disease diagnosed in the parent within a reasonable time after the diagnosis. If possible, this information is given by both parents. A child should be informed about the diagnosis without undue delay. The diagnosis should not be hidden from a child. A child should be offered the chance to talk to a specialist involved in the diagnostic process, which a child is unlikely to ask for. Professional, age-appropriate educational materials on FTD should be provided.
   b) Providing too much or too little information on FTD should be avoided. Flexible adapting of these contents to the current emotional and cognitive needs of a child should be implemented. In the case of particularly difficult issues, such as an unfavorable prognosis in FTD, the details related to disease progression or a family history, it is useful to gradually provide emotionally burdening information and to offer a child a chance to talk to a specialist involved in the treatment of the parent. Such a possibility should be offered to a child throughout the entire period of treatment.
   c) Allocating time to attentively contact a child and to listen to them. A child has a need to express their own thoughts and emotions. If a child has a sense of a secure relationship with an adult and is listened to, they will express their questions and concerns about their parent's disease. It should not be assumed that the lack of questions about FTD or concerns in the discussion means that a child does not have them.
   d) Younger children find it easier to express thoughts and emotions through play, creative activities (e.g., the book in the appendix to this paper) than a clearly structured conversation on a specific topic. It is important to observe a child during activities and to ask other people who spend time with the child about their observations related to the child's behavior.
   e) A child should be clearly assured that they did not contribute in any way to their parent's disease and the changes in the behavior of the affected parent are the symptoms of FTD.
   f) Telling the truth to a child.
   g) Undertaking issues that are not related to the disease in conversations with a child.

(2) Benefiting from social support by a family with FTD; avoiding social isolation [2, 4]:
   a) Social environment support is the factor that reduces the feeling of loneliness and contributes to healthy coping strategies of an adult and a child with a complex problem related to FTD. Providing support for a family

with FTD is the responsibility of professionals involved in the diagnostic process, treatment and care activities. It can be received from extended family, friends, school environment, etc., as long as the family informs about the situation. Other forms of support include a self-help group, telephone helpline, regular workshops for families with FTD, which are practically unavailable in Poland. A support group created by children from these families of a similar age category is helpful for children. However, self-help groups for caregivers of affected persons or caregivers of the elderly with dementia (i.e., extensively profiled) can be perceived by families with FTD as those focused on the problems that are too far from their life situation.

b) A family with FTD should receive assistance from others that could facilitate reorganization of daily life tasks e.g., transport of a child to/from school with their peer, therapeutic activities for a person with FTD conducted by a professional caregiver.

c) A child should be encouraged to maintain regular contact with at least one adult without FTD, other than the parent, e.g., a person from the extended family, a close friend of the family or a person from a support group for families with FTD. It will allow a child to strengthen the network of available support and to observe different patterns of adult behaviors.

d) A parent without FTD should model the ability to take care of their own needs, including social contacts, which next to taking care of a child and a person with FTD favors the development of healthy coping strategies by a child.

(3) A child should be supported in a way that meets their individual needs, developmental stage and shaping personality [2, 4, 10], which means that:

a) Adults should maintain the boundaries in the relationship with a child to prevent transferring responsibility for the emotional state of parents on a minor. A parent without FTD can seek emotional support related to the most difficult experiences from friends, extended family, specialists in FTD or a psychotherapist.

b) A child should be encouraged to engage in contact with their peers and participate in activities outside the home. The aim of such activities is to balance the emotionally burdening changes in the family due to FTD.

c) A child should be appreciated for their efforts and actions.

d) A child should be given understanding and acceptance for experiencing different emotions triggered by their parent's disease. Child's emotions, particularly anger, shame and disgust should not be judged.

e) A child should be given a choice about the information provided to their friends, which increases the sense of the influence on their own situation. In general, a child of a parent with FTD is not very willing to share the disease-related problems with children outside of their own family due

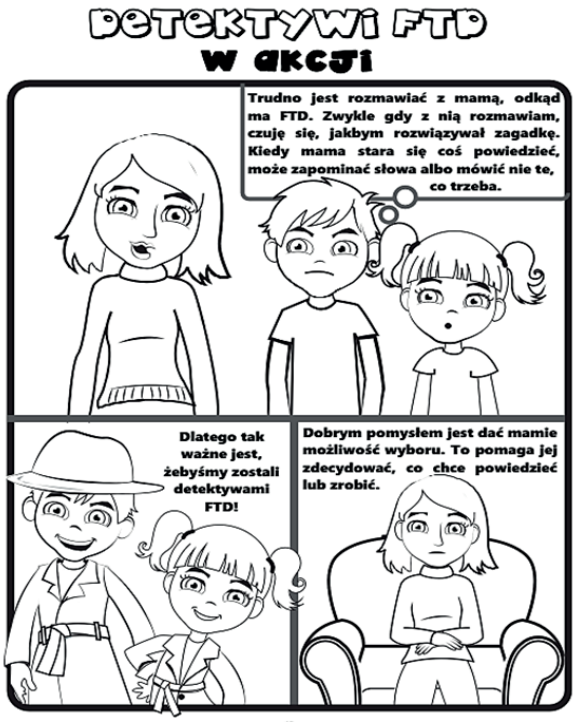
to the feeling of the lack of understanding. A child is more likely to rely on the support of siblings and a child from another family with FTD, if possible.

f) Child's preferences related to visits to a parent with FTD in a nursing home or hospice should be considered.

g) Changes in the child's behavior that suggest experiencing despair, grief or depression before or after the death of the affected parent should be identified early. If necessary, contact with a child and adolescent psychotherapist should be established.

"Filip and Tina – Detectives!"

The Polish edition of the book by Tiffany Chow and Gail Elliot [14] entitled "*Filip i Tina – Detektywami! Książeczka aktywności dla dzieci o zwyrodnieniu czołowo-skroniowym (FTD)*" was prepared by the authors of the paper with the approval and in cooperation with the authors of the book. The original English version was translated into Polish (S.P.) and the Polish version was consulted for the contents (M.A.-S.). Con-



Example: **Chow T, Elliot G. Filip i Tina – Detektywami! Książeczka aktywności dla dzieci o zwyrodnieniu czołowo-skroniowym (FTD). 2018. P. 12.**

formity of the translation with the source text was verified by bilingual persons who had lived in the United States of North America for years. In addition, the text was corrected by Polish philologists. The book is also available free of charge in English and in Welsh on the Internet at https://www.dementiability.com.

It is one of the examples of *graphic medicine* that provides medical information in the pictorial form of a comic book [18, 19]. The main characters of this book are Filip and Tina who are siblings and whose parent is diagnosed with FTD. Filip and Tina are the guides of a child from a family with FTD. Their role is to familiarize children, especially at early school age, with the neurodegenerative disease and to support children in a difficult process of coping with the disease of one of the closest persons to them. By performing the tasks from the book, a child acquires the skills of the FTD Detective. Shaping these abilities is based on a form of a comic book enriched by the tasks a child can do in the presence of both parents (if possible).

The choice of activities corresponds to the typical problems the children from families with FTD face in terms of behavioral and/or language symptoms of the affected parent. For example, the activities provide knowledge on the functioning of the brain and the brain areas that are impaired by FTD and also facilitate the discussion about emotions related to the disease of a parent. The book contains the FTD Detective Certificate that acknowledges the skills of a child that are useful in more effective coping with inevitable changes in the relationship with the affected parent.

We truly hope that Filip and Tina will reach children from Polish families with FTD.

References

1. American Psychiatric Association. *Kryteria diagnostyczne zaburzeń psychicznych DSM-5®*. Wroclaw: Edra Urban & Partner; 2018.
2. Barca ML, Thorsen K, Engedal K, Haugen PK, Johannessen A. *Nobody asked me how I felt: Experiences of adult children of persons with young-onset dementia*. Int. Psychogeriatr. 2014; 26(12): 1935–1944. https://doi.org/10.1017/S1041610213002639
3. Bidzan M, Rasmus A, Guzińska K. *Pomoc rodzinie chorego z otępieniem czołowo-skroniowym*. In: Pąchalska M, Bidzan L, editors. *Otępienie czołowo-skroniowe. Ujęcie interdyscyplinarne*. Krakow: Krakowska Akademia im. Andrzeja Frycza Modrzewskiego; 2012. P. 293–325.
4. Denny SS, Morhardt D, Gaul JE, Lester P, Andersen G, Higgins PJ et al. *Caring for children of parents with frontotemporal degeneration: A report of the AFTD Task Force on Families With Children*. Am. J. Alzheimers Dis. Other Demen. 2012; 27(8): 568–578. https://doi.org/10.1177/1533317512459791
5. Gelman C, Rhames K. *"I have to be both mother and father": The impact of young-onset dementia on the partner's parenting and the children's experience*. Dementia (London). 2020; 19(3): 676–690. https://doi.org/10.1177/1471301218783542
6. Millenaar JK, van Vliet D, Bakker C, Vernooij-Dassen MJFJ, Koopmans RTCM, Verhey FRJ, et al. *The experiences and needs of children living with a parent with young onset dementia: Results from the NeedYD study*. Int. Psychogeriatr. 2014; 26(12): 2001–2010. https://doi.org/10.1017/S1041610213001890

7. Rosness TA, Engedal K, Chemali Z. *Frontotemporal dementia: An updated clinician's guide*. J. Geriatr. Psychiatry Neurol. 2016; 29(5): 271–280. https://doi.org/10.1177/0891988716654986
8. Johannessen A, Engedal K, Thorsen K. *Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: A qualitative follow-up study*. Int. J. Qual. Stud. Health Well-being. 2016; 11: 30535. Published 2016 Apr 8. https://doi.org/10.3402/qhw.v11.30535
9. Johannessen A, Engedal K, Thorsen K. *Adult children of parents with young-onset dementia narrate the experiences of their youth through metaphors*. J. Multidiscip. Healthc. 2015; 8: 245–254. Published 2015 May 27. https://doi.org/10.2147/JMDH.S84069
10. Nichols KR, Fam D, Cook C, Pearce M, Elliot G, Baago S et al. *When dementia is in the house: Needs assessment survey for young caregivers*. Can. J. Neurol. Sci. 2013; 40(1): 21–28. https://doi.org/10.1017/S0317167100012907
11. Rasmussen H, Hellzen O, Stordal E, Enmarker I. *Family caregivers experiences of the pre-diagnostic stage in frontotemporal dementia*. Geriatr. Nurs. 2019; 40(3): 246–251. https://doi.org/10.1016/j.gerinurse.2018.10.006
12. The Association for Frontotemporal Degeneration. *The doctor thinks it's FTD. Now what? A guide for managing a new diagnosis*. 2013. www.theaftd.org
13. The Association for Frontotemporal Degeneration. *What about the kids? Frontotemporal degeneration: Information for parents with young children and teens.* 2012. www.theaftd.org
14. Chow T, Elliot G. *Frank and Tess – Detectives! A children's activity book about frontotemporal degeneration (FTD)*. 2012/2018. www.dementiability.com
15. Kaizik C, Caga J, Camino J, O'Connor CM, McKinnon C, Oyebode JR et al. *Factors underpinning caregiver burden in frontotemporal dementia differ in spouses and their children*. J. Alzheimers Dis. 2017; 56(3): 1109–1117. https://doi.org/10.3233/JAD-160852
16. Blandin K, Pepin R. *Dementia grief: A theoretical model of a unique grief experience*. Dementia (London). 2017; 16(1): 67–78. https://doi.org/10.1177/1471301215581081
17. Young JE, Klosko JS. *Program zmiany sposobu życia. Uwalnianie się z pułapek psychologicznych*. Warsaw: Wydawnictwo Zielone Drzewo, Instytut Psychologii Zdrowia PTP; 2012.
18. Green MJ, Myers KR. *Graphic medicine: Use of comics in medical education and patient care*. BMJ 2010; 340: c863. Published 2010 Mar 3. https://doi.org/10.1136/bmj.c863
19. Williams IC. *Graphic medicine: Comics as medical narrative*. Med Humanit. 2012; 38(1): 21–27. http://dx.doi.org/10.1136/medhum-2011-010093

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