

Writing, a formative activity for the patient

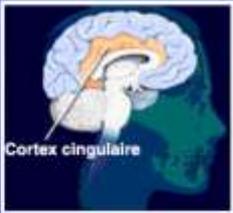
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«Have no fear of perfection, you will never reach it»
Salvador Dali

Sick people, whether in the hospital or at home, often suffer moments of physical pain which may be recurring and insurmountable or they may experience profound unease which renders their existence unbearable. Whether they be children, adults or the elderly, it is of the utmost importance that we, as caregivers, suggest ways of distracting them from their painful experience.

As a professional, it is self-evident that we wish to bring relief. The nurse is there to help patients in the face of their difficulties and empathy is an essential condition of the relationship between the caregiver and the patient. Thus it is natural that when we see someone suffer we seek whatever means we can to help them.

The cingulate cortex is activated when we feel pain as well as when we see someone else suffering pain.



Mirror neurons:
http://www.wikiquote.org/wiki/Mirror_neurons

A natural phenomenon

But it is not necessary to be a health care professional to do this. The aptitude for comprehending the other comes naturally to human beings. It involves two components: an innate and unconscious aptitude to feel what others are feeling [. . .] and a conscious capacity to put ourselves in the place of the other.^{1,2} This is what is known as empathy. But in the first case, the capacity to feel what the

other is feeling is rooted in the physiological properties of our nervous system which constructs its perceptions, among other things, from the action of *mirror neurons*.³

Research in neurology has demonstrated the presence of behaviour resonance mechanisms in humans. The team of Professor Giacomo Rizzolatti of the University of Parma in Italy, demonstrated that when we observe someone act or experience a situation, specialized neurons in our brain, the mirror neurons, spring into action. Their role is to enable us to

¹.Jean Decety, une spécificité humaine. Conférence. Le Monde :

http://www.lemonde.fr/web/imprimer_element/0,40-0@2-3328,50-331910,0.html.

². Jean Decety (2004). *Perspective Taking as the Royal Avenue to Empathy in Other Minds*. Guilford Publishers

³. *Les neurones miroirs*. <http://www.unice.fr/neurobiol/neurocomp/enseignement/grammont/acl/aclcours7.pdf>

understand the meaning of the other's behaviour.⁴ According to these scientists, the cerebral areas activated when we experience emotions are the same areas that are activated when we observe these emotions in our patients. Thus, when we tell someone that we understand what they are feeling, it is truer than we think. Subsequently, it seems logical to conclude that this might lead us to search for acceptable solutions for bringing relief to our patients. This need to help is in fact not extraordinary, it flows naturally from our human capacities. We have an entire panoply of medications and soothing acts at our disposal for the patient who is suffering, desperate or dying. But unfortunately, at times we need to look elsewhere, beyond our usual habits and find other, less conventional means.

Writing as therapy



The practice of a creative activity features the stimulation of concentration and liberation of the spirit in fantasy which has a beneficial effect on stress, anxiety, despair and even on physical suffering.⁵ Writing has this capacity to provide an outlet which delivers us from the day to day, and which opens our minds to reflection, self-expression and journeying in more poetic and more pleasant domains.

Whether it be via the essay, poetry, or a personal journal, all types of writing offer a formative activity for the patient and help to diminish their suffering. At times, we do not know what to suggest to a cancer patient who is suffering and haunted by the perspective of an uncertain future, or a depressive person who sees darkness everywhere and whose life consists of imperatives such as "I must do this or that", or an older patient who realizes that his faculties are on the decline. In all these cases, suggesting that they write their feelings and concerns, without forgetting to tell them to also note the positive experiences, even if it is only a ray of sunshine coming in through the window, may turn out to be constructive. The nurse is not a specialized therapist but can occasionally, according to the need, in a completely normal and human fashion, suggest activities that might help the patient.

The advantages of writing in the practice of nursing

As nurses, especially in hospitals, we are used to suggesting conventional interventions, generally of a technical nature, but even at times of a relational nature. Our panoply of tests, medications, dressings and various actions is very large. But at times special needs crop up, which require different means from those which are most familiar to us. For example, in mental health units, with cancer patients or those suffering from disabling chronic illnesses or a handicap, we must seek means which favour self-expression, which create a distance from suffering and provoke a diversion even if it is only for a moment. Certain health centres have workshops in art, crafts, do-it-yourself projects, or motivation or recreation services, but these activities, albeit very helpful, are generally social and often superficial, and the aim of

⁴. Giacomo Rizzolatti et Gordano Sinigaglia (2008). *Les neurones miroirs*. Paris, Odile Jacob, p. 137.

⁵. Margot Phaneuf. Creativity at the nurse's service. <http://www.prendresoins.org/?p=2125>

connecting with the person in the depths of their discomfort is not always achieved. Moreover, these services are not available everywhere.

Writing as an means of liberation

In certain cases, and for certain patients, suggesting that they write may at first seem difficult and even impossible. However, once they begin, patients often find in writing an escape, a momentary flight from their daily reality which quickly becomes an important ally against the stress of the illness, the tensions inherent in physical suffering and the sadness associated with mourning and depression.

Illness, whether it be physical or psychological, is a genuine burden which limits one's daily activities and often even alters human relationships. To find an outlet, a place where all the things one cannot say can be expressed, brings relief, helps us to understand and often better accept the unacceptable. There is obviously the effect of diversion which, because of the attention and concentration required to write, helps us to forget, which is an important factor in itself.

The autotelic fonction of writing

An author on the psychology of happiness, Csikszentmihalyi, provides an explanation of this



phenomenon when he states that an intense investment in a task, an ardent desire to do it, momentarily imbues what we are doing with meaning which flows beyond to affect our entire lives.⁶

The author calls “*flow*”, these moments of grace when, involved in writing or doing some other task, we are totally immersed in the experience, and intensely concentrated to give the best of

ourselves. The word “flow” brings to mind an image of facility, ease, serenity, liberty, recalling the peaceful flow of a river.⁷

But the term “flow” can also become an allegory of the spontaneous gush of a source, an outpouring of creativity, the Muse of arts and letters. This state of attention, of total absorption in a task, modifies our state of consciousness. It helps us to transcend difficulties

⁶. Mihaly Csikszentmihalyi (2006) *Mieux vivre*. Paris Pocket

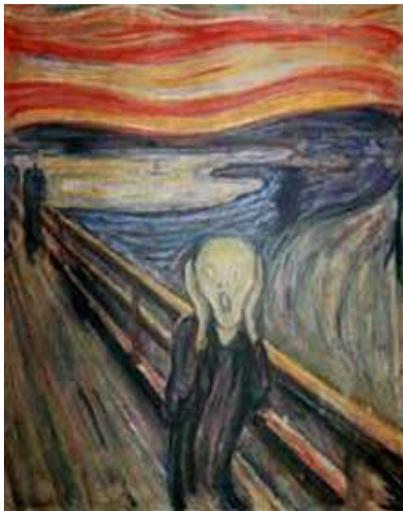
⁷. Claude Monet. *Nymphéas*. Pinacothèque de Munich : http://www.insecula.com/oeuvre/photo_ME0000071293.html

to the point of altering our perception of time. We forget the hours that have passed, the effort furnished, the pain and our current preoccupations.

This state also confers a feeling of fluidity, of facility, of self-confidence and competence in the face of the work which must be done or the difficult situation which must be managed. For Csikszentmihalyi, to transform routine into pleasure, enables us to invest intensely in each moment and renders our existence more pleasurable. The author calls this an *autotelic activity* that is, an occupation which is an end in itself and where the pleasure of doing it is more important than the objective pursued. In the case of writing, it is the freedom and the narcissistic happiness of being able to go inward, to discover and express oneself without limit, which goes beyond the ostensible objective of writing a letter, a diary or a poem.⁸

Writing as a means of externalizing suffering

Anger, exasperation, and despair in the face of a painful situation are at times so intense that they totally overwhelm the person in a vague, not corticalized manner, staying on the level of the limbic brain where our emotions are located and not coming up to the logical level of the cerebral cortex. Attention is thus totally centred on the painfulness of the situation where it completely overwhelms our field of consciousness. Thus, concentration on something else, for example, writing, can lead to a beneficial dissociation. (Image).⁹



Psychological pain and suffering, when they are put down black on white, whether on paper or on the computer, are thus objectified. They become like exterior objects from which we can dissociate ourselves, that we can examine, describe, and by doing so, control them. We are in the face of what Freud called the “observing mind”.¹⁰ This intense investment in an observation or an activity executed while we are dissociated from our feelings, seems to tell our organism that our investment in concentration is more important than the pain signal. The dissociation opposes the suffering which overwhelms our field of consciousness, facilitates the evacuation of tensions and, at the same time, enables our lucidity to come to the fore in this painful

jumble. It helps us to see the situation more clearly and to comprehend it better, and as a result, to better manage it.

There are many testimonials to this including the prestigious Journal of the American Medical Association, which recently published a study demonstrating that writing could have a

⁸ . Mihaly Csikszentmihalyi (1990). *Flow: The psychology of optimal experience*. New York: Harper and Row.

⁹ Edward Munch. *Le cri*. Musée d’Oslo. Sur le site radiofranceinternational (RFI).

http://www.rfi.fr/actufr/articles/056/article_30007.asp

¹⁰. Thierry Simonelli. *L’Esquisse d’une psychologie scientifique* :

<http://www.psychanalyse.lu/articles/SimonelliEsquisse03.htm>

profound influence on physical suffering. Patients suffering from asthma or arthritis had to describe the most difficult moment of their lives. Four months later, those who had worked on their difficulties for twenty minutes for three successive days felt better, took less medication to relieve their symptoms and saw their doctor less often! If there was a pill which had such an effect after only three administrations not a single doctor would fail to prescribe it.¹¹ We don't have to worry about suggesting this kind of activity to our patients!

What we should watch for and above all, avoid

Writing has an advantage over other art forms in that not much material is required and it can be easily done in a hospital setting. As for all other nursing interventions, the nurse should explain the objective to the patient, support their effort with questions and positive reinforcement and follow the evolution of the experience. The nurse should evaluate the results and if necessary, manage the possible accidental deviations. The patient may for example strive for a quality of writing which they cannot accomplish, which risks discouraging them and taking them away from the pursued objective of relaxation and distancing themselves from their pain. It can also happen that the depressed patient may tirelessly ruminate on the negative moments of their life and thus keep turning the knife in the wounds of their existence. These sad ruminations are no more helpful in writing than in speech. As one can see, the exercise of writing recommended by the nurse must be supervised and evaluated.

“They do not see the rose for their attention is on the thorns.” Lucien de Samosate
Comment il faut écrire l'histoire

Writing and the patient with cancer

Among the patients who can profit most from writing, the cancer patient is certainly one of the most obvious. They are suffering, they have the impression that their lives have come to an end for their future is uncertain and chemotherapy is painful. How do we help them deal with this reality? They need to find an activity which will help them verbalize the despair that they cannot express otherwise, an activity where they can forget the obligations and uncertainties of their daily lives, and make contact with their inner resources and use their creative potential.¹² Whatever the mode of expression chosen, it must enable them to convey their suffering and by reflecting on it, to speak about themselves and their desire to let go or their capacity to recover.

Christian Lamontagne, in his article, “**La maladie révélatrice** » wrote that people suffering from cancer “suddenly finds themselves in a sort of initiation rite which will transform their lives forever”.¹³ He explains, as does Richard Moss,¹⁴ that if they choose to do so, they have

¹¹. David Servan-Schreiber (2000). *Ecrire pour guérir un peu* :

<http://www.psychologies.com/chroniques.cfm/chronique/127/Ecrire-pour-guerir-un-peu.htm>

¹². Louise Provin (2004) *L'urgence de vivre*, Laval, Éditions Publistar, p. 158

¹³. Christian Lamontagne. *La maladie révélatrice*. Passeportsanté.net :

http://www.passeportsante.net/fr/Maux/Problemes/ArticleInteret.aspx?doc=cancer_lamontagne_c_1993_pm

¹⁴. Richard Moss, doctor and writer who is working on the conscience's awakening.

the possibility to undergo this traumatizing experience as a ritual passage which will lead them to discover higher values of consciousness or they can let themselves be dominated by the overwhelming events of their painful ordeal. It's a question of choice.

Illness is in a way a mirror of the conditions of our life and it is now commonly accepted that



it may represent an inner conflict which can find no other way to express itself. The main risk factors are the stresses caused by difficult family or work relationships, or those associated with a lack of self-esteem or a deterioration of the reasons for living.¹⁵

Furthermore, cancer patients, even lovingly surrounded by their family, feel isolated for it is alone that they must fight this disease... and giving them a way to express their emotions, their conflicts, to discover their inner self and their barriers cannot but be helpful.

At first, the process may seem difficult for those who have never been able to express themselves, for they must find the unknown road of their inner life and invent a language which is new for them, in order to voice their hopes and feelings. But with a bit of encouragement and lots of support, many succeed. Several modes of expression may be suggested according to the person's tastes and choices, there are no rules. Whether it be a personal journal, also known as a therapy diary, an essay, letters to those in whom they have confidence, letters which will never be sent or even poetry, these literary exercises all have the same powers of diversion, dissociation, distancing oneself from one's suffering and expressing oneself.

Patients with chronic illnesses

The patient with a long painful disease for which there is no hope of healing often experiences discouragement and anger. Beyond the suffering, they know that despite the treatments, the time left to them is more or less long. But, as stated by Victor Frankl in his book, it is probably the loss of meaning in the face of an inescapable situation which demoralizes them the most.¹⁶

Generally speaking, those who suffer from chronic illnesses, such as diabetes, arthritis, multiple sclerosis, fibromyalgia, Parkinson's or cardiac or respiratory illnesses, put up a good front and try to show their loved ones that they are dealing with their illness. However, no matter how stoic they may appear they all experience negative emotions and at times great suffering which they do not often express. One must not forget that in all these illnesses the emotional element is very important, especially since the physical difficulties and the

¹⁵. Image. Kokian Gallery. Pain : http://www.kokian.com/article.php3?id_article=16

¹⁶. Viktor Frankl (2006). *Découvrir un sens à sa vie*, Les Editions de l'Homme, Québec, 2006.

resulting suffering cause a social rupture in their daily habits and their relationships.¹⁷ For these patients, writing down their torments and verbalizing their daily suffering, constitutes a distraction and puts their situation in perspective which helps them to negotiate with the present moment and with whatever time is left to them . . .

Psychiatric patients and their relationship to writing

Since the beginning of time, tormented authors have expressed their suffering by writing, which offered them an outlet. This still holds today; the person suffering psychological difficulties can find in writing, a confidante to whom they can pour out their thoughts and feelings, an appeasement for their worries and even a way of reappropriating themselves and their inner life.¹⁸



Very often, these patients feel a great need to speak to someone who can understand them. But where does one find this gem? Parents and friends are often overwhelmed and indifferent, and may even lack all empathy when they cannot see any physical manifestation of an illness. To speak freely, without being judged, becomes necessary and even easy in writing. The therapeutic effect arises from the freedom that it gives to those who use it.

In a personal journal or any other form of writing we can say all that crosses our minds: impressions, fears, resentments, we can denounce injustices, express our anger, and even share our joys and hopes. The simple fact of sharing what we are experiencing, putting it in words, already objectifies our suffering and puts it at a distance. Relief follows, an evacuation of somber ideas which delivers us, at least partially, from the weight of our distress and even the wish to end it all.

For the psychiatric patient, writing may take many forms. Poetry, for example, if they want, may be a special means of escape. Unsent letters are also another means by which they can say to others, for example their parents or friends, what they think and what they have been suffering for a long time, without fearing their reactions. It is an excellent means of liberation. Essays and stories may also be appropriate if the person feels that this medium suits them.

The depressive patient may particularly benefit from writing. Especially if they are supported to not just masochistically cultivate their difficulties. Moreover, since depression drains their energy, they need to be stimulated to write by explaining to them the benefits of writing. It is also important to mention that it is not necessary to write for a long time,

¹⁷. Jean Foucart (2002). *Sociologie de la souffrance*. Bruxelles, DeBoeck Université, P. 38-39.

¹⁸. Vincent Van Gogh. *Nuit étoilée* :

<http://www.3dsr.com/vangogh/peintures%20de%20vincent%20vangogh.php>

especially at the beginning and that style is of no importance. What counts is not the result but the road taken.

Those suffering from other psychiatric problems also find a saving grace in writing. Whether they suffer from phobias, manic-depression, anxiety, emotional or food related problems, obsessions or alcoholism, or those related to drugs or personality, confiding their difficulties or their dreams to a diary or any other type of writing, cannot but help them.

It is important that the psychiatric patient not sink into their writing like a drowning person into troubled waters. It is helpful to talk with them in order to avoid that they become enclosed in a painful bubble. Writing is an intervention which, like all others, needs to be supervised and evaluated. It would be too bad if the cure was worse than the disease.

The patient with cognitive deficiencies and their capacity to write

It may seem surprising to suggest writing for a patient who is losing their cognitive capacity. However, whether it be Alzheimers or any other type of pathology, these patients do not lose all of their capacities at once. Since these illnesses often progress slowly, the person maintains their capacity to write for a long time. As they see that their faculties are disappearing they often experience great suffering which needs to be expressed. Depression, despair, solitude and fear fill them daily and confiding in a notebook or a computer becomes for them a means not only to confide but also to recover the capacities which they know are vanishing.¹⁹



Keeping a personal journal stimulates their memory of words, persons and events; moreover, the movement needed to write, maintains certain mobility. For the aging patient, as well as all the others, we must inform them of the benefits of writing and provide some simple directives. We should encourage them and praise their efforts. The diary is not the only form of writing which they can do, letters, poems or short articles for the establishments' newsletter are also useful forms.²⁰

The patient at the end of life

In the departments specializing in palliative care, it is taken as given that those who are at the last stage of their lives find tremendous relief in expressing themselves by writing while they still have the strength to do so. They can thus examine their lives, discourse with themselves about death and in a sense, get used to death. In this way they can consider their life from all

¹⁹. Margot Phaneuf (2007). *Le vieillissement perturbé. La maladie d'Alzheimer*. Montréal, Chenelière-Éducation, p. 161-162

²⁰. Image. Vincent Van Gogh. *Mélancolie*

angles, put their joys and sorrows in perspective and reappropriate the various stages of their life. The reflection inherent in writing also favours the emergence of higher values and helps them find meaning in their suffering. As for the other illnesses, writing calms the patient and often leads them to feel less pain.

Whenever possible, everywhere where patients move towards death, whether it be in medical or surgical units, or at home, putting their thoughts or their existential worries on paper, often succeeds in calming them and seeing with serenity what is left for them to do or to say to their loved ones. Writing thus takes on a concrete, dramatic aspect, becoming almost a precious heritage for the family.

For all these reasons, recommending writing to a person at the end of their life has a good

“Writing is also not speaking. It is keeping silent. It is screaming without a sound”.
Marguerite Duras,
extract from *Écrire*

chance of producing beneficial effects. One must however, incite these patients not to go beyond their physical strength and if possible, share their reactions with their caregiver. One must avoid that the recounting of the events of their lives lead them to cultivate guilt. The aim is to bring greater serenity and not to awaken their consciousness of having acted badly or not having done all that was possible. One must take care, because

as Victor Hugo once wrote, “memory is at times first cousin to remorse”.²¹

The various means by which we can help our patients

Writing as a means of helping our patients can take different aspects: a personal journal in its various forms, poetry, epistles and letters which are not sent, essays, novels, and children’s stories. All these ways of expressing one’s thoughts and feelings are helpful. One must determine the capacities of the person and orient them according to their preferences and capabilities.

The personal journal

The personal journal is an extraordinary method which can be proposed to patients who are experiencing different problems. It enables them to vent their emotions, to put on paper or in the computer things which they would not have dared tell anyone. This method can take several forms. For example, the patient can simply write in a special notebook the events of the day and their reflections on them. This form has many advantages but its therapeutic effects are limited.

The intensive or creative journal brings greater benefits for the patient. It requires more reflection and a greater investment in the examination of their thoughts, actions and above all in the expression of suffering and the interrogation of its causes and the means to appease it. During the sixties, the psychotherapist, Ira Progoff promulgated the *Intensive Journal*

²¹. Victor Hugo. *Les contemplations*. Paris, Hachete, 1858.

Method which has helped millions of people.²² The aim of this type of journal is to incite the person to contemplate their intimate processes, which are revealed through the act of writing, to question their relations with others and to promote their own growth. It is not a masochistic revision of their sufferings and difficulties, but rather a contact with themselves, the discovery of their deepest values and the beginning of a change.

Another variant of the personal journal is the **therapeutic journal**, developed by Katleen Adams in Colorado who was inspired by the work of Doctor Progoff and which goes beyond the simple reconstruction of one's life. Its objective is to liberate the interior tensions and to perceive more clearly the road to follow.²³ This method puts the emphasis on different themes such as one's dreams, work, family, human relationships, inner and spiritual life, in order to explore and deepen them and by so doing to reach a higher level of consciousness.

Bruno Fortin wrote that "scientific research indicates that the emotional expression once written down is associated with an improvement in the state of health of several variables. Smyth (1998) reports this effect mainly with people in good health. Pennebaker and Beall (1986) stimulated research in this domain after having noted a significant difference between a group where the participants wrote down their deepest thoughts about a traumatic event and a group where the participants wrote only their plans for the day".^{24, 25, 26} Pennebaker's research even showed that writing for twenty minutes per day, for three or four consecutive days, on the events and emotions which perturbed the person, reinforced their immune system.²⁷

The evolution which takes place during the writing of a journal

Beyond creating a diversion and objectifying pain, the journal gives rise to constructive spin-offs which are manifested in a progressive manner. When patients first begin to keep a journal, they are mostly preoccupied with writing down their strongest emotions. They often write down their impressions in some kind of a jumble, their revolt against the fate that the disease has brought them, their hatred for the people who have hurt them or their despair in seeing themselves in the situation in which they find themselves. This is the moment of **catharsis**, a violent emotional liberation which follows the expression of traumatic emotions and memories.

²². Maritha Pottenger. *Ira Progoff: Learning to Listen to One's Inner Rhythms*:
http://www.ccrsdodona.org/m_dilemma/1980/gem/rhythms.html

²³. Céline Ferjoux. *Les journaux intimes sur Internet*. DESS 2000-2001 :
http://www.nomedial.org/docs/jrnx_intimes_cferjoux.pdf

²⁴ Bruno Fortin. *Les émotions et la santé* :

http://www.ordrepsy.qc.ca/opqv2/File/pub_psychologie_quebec/janvier_2002/ArtDossier_Emotions_Janv02.pdf

²⁵. J. M. Smyth. « *Written emotional expression: effect sizes, outcome types and moderating variables*. » Journal of Consulting and Clinical Psychology, 66, 1, 1998, p. 174-184.

²⁶. J.W. Pennebaker. *Emotion, Disclosure, and Health*. Washington, DC, American Psychological Association, 1995.

²⁷²⁷. J.W. Pennebaker et Beall, S. K. « *Confronting a traumatic event: toward an understanding of inhibition and disease*. » Journal of Abnormal Psychology, 95, 1986, p. 274-281.

After this stage, the person becomes more serene, can deepen certain reactions, analyse through their writing their relations with others, the circumstances and consequences of the events which have marked them or question certain of their behaviours concerning their health, their nutrition, their way they treat others or their relationships with them. This is the stage of **becoming self aware**.

Next comes a more positive moment where the person turns their reflection towards the means of change and the betterment of their relations with others, the search for behaviours of health, acceptance, and fidelity to the treatment and the increase of their well-being when that is possible. This is the stage of *constructive change*. In order to help the person follow this progression, the nurse can suggest themes to develop in their writing in accordance with the type of physical or mental problem that is present.

**“Take all the time you need to know yourself . . . discovering yourself is in itself a journey.
Gilles Vigneault
Je viens d’écrire une lettre.”**

The journal thus becomes a means of discovering up to now unknown aspects of oneself because it is a continual questioning, an exploration of one’s life in its diverse aspects. But above all, it empowers the patient with regards to their situation. By better defining it, they see their situation in a new light and can better manage it. The act of writing, putting one’s difficulties into words, creates the impression that one is active and in control of one’s painful experiences, and this gives meaning to what is happening.

Epistolary writing

Writing letters to our family and friends may also become an important means of diversion and liberation. When the person can find interesting writing partners in their milieu, they can confide themselves, communicate their suffering, find a means of distraction and lighten the climate of heaviness which penetrates each instant of their lives. The interest manifested by others towards them can act as a balm on painful wounds.

Unsent letters

When patients have an urgent need to confide themselves and there are no meaningful correspondants, one can suggest writing letters which will not be sent. In this case the objective is one of diversion and the liberation of emotions rather than an exchange of letters. This method is above all useful in situations where the person has been hurt, maltreated or abandoned by someone in their family circle and they would like to settle their differences without having to worry about being judged or the reactions which may be provoked. They can thus express all their anger and even hatred towards someone that they do not wish to contact or even towards those who are dead. It is a means of letting off steam, a salutary catharsis for those who have been traumatized by their life experiences.

A piece of paper or a keyboard can take it all: anger, hatred, boredom and even extreme suffering . . .

A guided autobiography, an alternative

The guided autobiography is a bit different from a personal journal or diary. It is especially useful for those who are losing their cognitive autonomy. It is an adaptation of the memoir. It stimulates memories, the integration of past experiences with the present and often allows the person to make sense of former events which were buried under the details of their daily lives. It is important to allow the person enough time to dig into their memories and not to have too high expectations.²⁸

The guided autobiography is more systematic and chronological than a simple evocation of memories or a diary. To help the patient write it, it is often useful to propose themes, for example:

- The family history.
- Their love lives.
- The description of their work or professional life.
- The importance of the love of their loved ones.
- The value of money in their lives.
- The importance of friendship in their life.
- What good health enabled them to accomplish.
- What they accomplished by helping others or being helped by others.
- A funny event in their lives.
- A fearful event or situation.
- Love of nature.
- A portrait of their best friend, their spouse, parents, etc.
- Their greatest success.
- Their greatest hope
- Their greatest happiness.

**«Write hard and clear about what hurts.»
Hemingway**

Writing despite a major handicap: using another medium

**“To write is to confront an unknown image of oneself”
Edmond Jabès
Les Cahiers du double**

Certain persons, because of an important physical problem, or a psychological or mental difficulty, are unable to write. For example, patients left paralysed after a stroke, the handicapped or those losing their cognitive autonomy, or who have lost their capacity to express themselves verbally, are persons who cannot write by themselves. These people have not lost all their means and above all have not lost their desire to communicate. Recourse to a facilitating strategy somewhat similar to the one used by Anne-Marguerite Vexiau with autistic children may be a solution.²⁹

This is a strategy enabling certain individuals affected by manual motor limitations or problems of communication, to draw, with the help of symbols, letters or even words, in order

²⁸.Margot Phaneuf (2007). *Le vieillissement perturbé. La maladie d'Alzheimer*. Montréal, Chenelière-Éducation, p.163

²⁹. Anne-Marguerite Vexiau (1996). *Je choisis ta main pour parler*. Laffont, p. 323-324

to communicate. Someone can even hold their hand which holds the pen or the index finger which leans on the keys of a computer keyboard in order that they can write. Expressing oneself can bring great happiness to those who are enclosed in their inner worlds.

In certain cases, it is also possible to develop a gestual code which translates their thoughts which are brought out by a helper. By using this technique Jean-Dominique Bauby, the author of the wonderful book, “The diving bell and the butterfly” succeeded in communicating with his therapist despite the locked-in syndrome.³⁰ He was prisoner of his paralysed body even though his consciousness was intact. He was only able to move his left eyelid. By blinking his eyes, he managed to communicate with his entourage and to dictate his book. He blinked his eyelid once for “yes” and twice for “no” as his interlocuter pointed to the various letters of the alphabet and in so doing formed words and sentences. He undertook a long and patient endeavour with his orthophonist every morning for weeks on end where he dictated the words, lines and pages of the book he wanted to write by blinking his eyelid.^{31, 32}

This extreme example is beautiful, but it is obvious that the nurse does not have the time to invest so intensively with each patient however, it is possible, with the family or a volunteer worker, to find the means to help the patient who wants to communicate what they are experiencing and to express themselves despite their handicap. It often happens that even in situations which may appear desperate, it is possible to find some means which enable the person to exteriorise their thoughts, at least minimally, because the ability to express ourselves indicates that we are still alive.

Other literary means at hand

There are also other literary means which can be used by patients but they are not necessarily available to all. Poetry, for example, by favoring dream states and evasion, can be liberating. But it is often underutilised because it is perceived as being too difficult. We think that we are unable to rhyme when even children do it. We just need to let ourselves go! After all, the patient is not writing for posterity!

There are also short stories and essays. These are all means of exercising one’s pen and finding a diversion from a painful situation.

The requirements for writing

It is insufficient to suggest to our patients that they write. It is important to note that this type of intervention has some basic requirements. One must remember that:

³⁰. Lock-in-syndrome is secondary to a bilateral attack of the low part of the protuberance of the basilar trunk causing a motor paralysis of all the body. The person cannot communicate, except sometimes with a codified eye’s movements. Translated from Vulgaris-médical : <http://www.vulgaris-medical.com/encyclopedie/locked-in-syndrome-2832.html>

³¹. Jean-Dominique Bauby 1997). Le scaphandre et le papillon. Paris, Laffont

³². Carrefour culturel et humanitaire, section Carnets de lecture : <http://www.infiressources.ca/fer/depotdocuments/Le%20scaphandre%20et%20le%20papillon%20J-D%20Bauby.pdf>

- the patient needs a few basic explanations before understanding what needs to be done;
- they need some materials: a notebook, pencils and pens, paper or a computer for which one often one needs to solicit their family;
- it is important to motivate and encourage them;
- it is important to present this activity as a therapeutic method of personal reconstruction;
- it is helpful to propose themes such as:
 - relating and commenting on the events of each day;
 - remembering different stages of their lives;
 - establishing a dialogue with a loved one;
 - relating their dreams and desires;
 - establishing a conversation with their body and their illness;
- it is also necessary to furnish certain useful indications such as:
 - suggesting that they be brief and not go beyond their strength;
 - tell them not to worry about their handwriting or spelling;
 - incite them to write regularly for at least fifteen minutes, three times a week;
 - if necessary, remind them to write;
 - explain that it gets easier with practice;
 - insist that the person write their positive comments with respect to their life and themselves;
 - let the person choose whether to keep their writing to themselves or to share it with the nurse;
 - congratulate them for their effort.

After having written their journal or any other form of writing, the person is often more open and can thus benefit from the establishment of a more significant contact.

When the voice must replace the pen

When the pen can no longer carry our words, the voice can pick up the slack. Certain persons cannot write either because they are illiterate or too weak, but they are capable of expressing themselves in order to explore their experience of being ill. If they wish to do so, the use of a cassette tape-recorder enables them to verbally communicate their thoughts, to describe their suffering and to find diversion and the liberation which brings relief

Conclusion

In the face of physical pain, especially if it perdures, and in a situation where suffering is such that it totally impregnates the life of the patient, proposing that they write is a nursing intervention of choice and one which we do not often think of. Our panoply of habitual interventions is mostly associated with technical gestures and coming close to relational interventions makes us feel insecure.

We invoke an overload of work, the sacrosanct excuse which we use all the time when new methods, which involve using non-conformist methods, are proposed. But, recommending an intervention and furnishing a few explanations is not too demanding.

There is also the complexity of the medium which is another easy pretext. This is in fact an evasion in the sense that uncommon methods frighten us because we are unfamiliar with them. The latter reason can be easily understood but as Seneca wrote a long long time ago: “it is not because things are difficult that we do not dare to do them. It is because we do not dare to do them that they are difficult.”³³

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