

A PATTERN LANGUAGE FOR LIVING WELL WITH DEMENTIA: WORDS FOR A JOURNEY

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ABSTRACT

In this paper, we presents a pattern language for living well with dementia, which consists of 40 patterns that will come in handy for living well with dementia. These patterns have been constructed as the result of interviews with dementia patients, their families, and people who support the cause. The 40 patterns are called “*Words for a Journey*,” because our hope is that dementia patients and the people around them will use the words as guides to the adventure of living well with dementia.

INTRODUCTION

Dementia is something we all should be familiar with. Of the elderly people over 65 years of age in Japan, including those with mild symptoms, over 8 million have dementia. These statistics reveal that 1 in 4 elderly or 1 in 15 Japanese overall have dementia. If you walk through any given neighborhood, chances are high that many of them contain dementia patients and family members who care for them. Now, you should have an idea of how close everyone is to the disease.

Although many people still think that living with dementia is dark and hopeless, there are many with dementia who are living well (Bryden, 2005, 2012). They have not given up everything in their lives just because they have the disease. It is a fact that you will have to make some changes in your lifestyle once you have been diagnosed with dementia; but try looking at it this way: if you are going to have to make changes, why not make good ones? Think of it as the start of a new journey: a journey to live well with dementia. By spending more time with your family, you will get to know them even better. The time that is approaching is not a time to lose what you have, but a time to gain even more. How you

spend this time is completely up to you and your family.

In this paper, we presents a new pattern language consisting of 40 patterns that will come in handy for living well with dementia. In what follows, we will show the structure of patterns, and how to use them.

A PATTERN LANGUAGE FOR LIVING WELL WITH DEMENTIA

In our pattern language, positive, practical hints for living well with dementia are written in a pattern form. These hints were determined through interviews, meaning that there are people who are living well with dementia by using this knowledge (Figure 1). By sharing these wisdoms with a broad audience, our hope is to make everyone’s life with dementia better.

Each pattern describes a *context* that people with dementia and the people around experience and a *problem* that is commonly associated with the situation. Following this, a *solution* on how to cope with the problem is described, which then is given a *pattern name* (Iba, 2014).



Figure 1: Pattern mining by interviewing with the people with dementia and the family

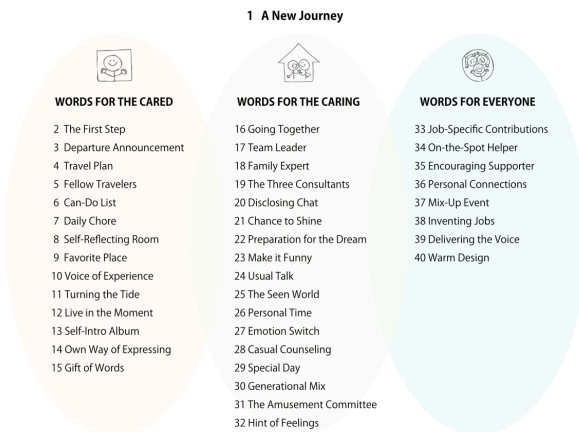


Figure 2: Three categories: the cared, the caring, and for everyone.

The patterns are categorized into three groups (Figure 2): “WORDS FOR THE CARED” (the person with dementia), “WORDS FOR THE CARING” (the patient’s family), and “WORDS FOR EVERYONE” (society in general). Each group contains words that provide problems and solutions for the person in the corresponding group.

You can start by reading words from your own group, but do go ahead and take time to read the words from the other groups as well. You should be able to take a peek at the problems and hopes that people in the other groups might be feeling. That way you should become one step closer to helping people from all three groups to live well with dementia.

HOW TO USE PATTERNS

There are two ways that the pattern language can be used. First, you can read through the collection of patterns and put those that you find interesting or useful into practice. Though each word is based on the experience of actual dementia patients and people close to them, there is no need to practice it in the same way. You can practice all or part of a hint based on how much it sympathizes with the pattern that you experience. This should become an opportunity for you to take a new action for positive change that you otherwise would not have taken.

The second way you can use the pattern is to use them as a part of your vocabulary to speak with other people about the hint that is described (Figure 3). You can talk about your own experience with one of the words to someone else or you can listen to their experience with the word. Conversations such as “Which word do you find most helpful?” “I think it is very important to give them a ‘Chance to Shine’,” “I don’t quite get how to use ‘Voice of Experience.’ Could you tell me how you are doing it?” can be conducted. Through the talks, you may be able to gain new ideas from other people for applying the

hints. In addition, using the pattern language to talk out loud about your experiences will help you organize your thoughts, and other people would then be better able to understand and benefit from your experiences.

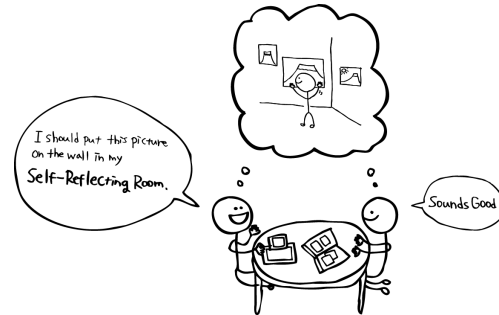


Figure 3: Patterns of Words for a Journey can be used as shared vocabulary

CONCLUSIONS

In this paper, we presented a pattern language for living well with dementia, which consists of 40 patterns. We are still searching for more “words for a journey” for living well with dementia. Some of you may have original “words for a journey” in mind. There should be even more “seeds” for possible new words in your daily life too. We will continue our search for new “words for a journey” together with you readers in order to keep updating our collection of words.

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