VERSION 1.0 | NOVEMBER 2018

UNIVERSITÉ LAVAL

Decision Box

Stress in Caregivers of Older Adults

Choosing a support option

THIS DOCUMENT IS AIMED AT...

- Friend or family caregivers of older adults living in the community

THIS DOCUMENT IS DESIGNED TO...

- Inform caregivers of the benefits and harms of their options to prevent stress
- Prepare caregivers to discuss their options with healthcare professionals
- Help caregivers choose an option that respects their priorities

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INTRODUCTION

EXPLORING THE OPTIONS TO LIMIT YOUR STRESS

Caregiver stress

Caregiving consists of taking on an **unpaid caring role for a person who has lost their mobility**, their ability to care for themselves, or their ability to undertake other essential tasks such as using the phone or managing their money. While **fulfilling**, caregiving **requires time and energy**, and **can be demanding and stressful. As a caregiver, it is important to pay attention to warning signs of stress:** feelings of anger, anxiety, depression, exhaustion, lack of sleep or concentration, health problems, or social withdrawal.

Risk factors for stress

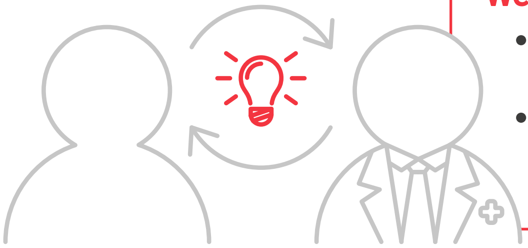
Some things increase the odds of caregivers experiencing stress, for example:

- if you **live with the person in your care**
- if you **have health issues** of your own
- if you **work part-time** or **have had to stop working**
- if you **lack the training** to perform the required caregiving tasks
- if you are **isolated** from your friends or family
- if the person in your care has **behavioural issues**
- if the person in your care has **significant needs**
- if you experience **conflicts** with the person in your care.

Taking your priorities into account

Depending on your priorities, **you may or may not decide to make a change**. The choice is **up to you** because...

- There are **several options** to reduce your stress. These options can cause **benefits** or **harms. It is difficult to predict how they will work for you.**
- Several factors may limit your ability to decrease your stress.
- **You can decide to give up your role as caregiver:** this may cause other stressful situations, but it is also one of your options.
- Choosing a support option or waiting before making a change (also called "watchful waiting") are **both acceptable options**.



We recommend that...

- The decision take into account the caregiver's values and priorities.
- The decision be shared between the healthcare professional and the caregiver.

OPTIONS
Explore the options

Physical Activity

Physical activity programs may include **walking, water exercises, balance or flexibility exercises, and weight training**. They can be done **at home or with other people**. The activities should produce a sensation of warmth, and make you breathe harder. You should still be able to hold a conversation while doing the activity, but not to sing.

BENEFITS

↑ Well-being ⊕⊕○○

Caregivers who are physically active on a regular basis are **more likely to experience well-being** than those who are not.

↓ Depressive symptoms ⊕○○○

Caregivers who are physically active on a regular basis are **less likely to experience depressive symptoms** than those who are not.

↓ Stress ⊕○○○

Caregivers who are physically active on a regular basis are **less likely to experience stress** than those who are not.

HARMS

↓ Sticking to the exercise program ○○○○

For every 100 caregivers who start a regular exercise program, **0 to 30 are off** it before the end, depending on the study. **More will stick to the program in home-based programs** compared to group-based programs.

Caregivers generally stop participating in exercise programs because **they lack time**.

↑ Injury ○○○○

For every 100 individuals who are physically active, about 15 experience an **injury** due to physical activity.

PRATICAL ISSUES

Time required ⊘

In general, to experience positive impacts from physical activity, people must be physically active at least 3 weeks, either for 20 minutes 3 times a week, or for 2 hours once a week. Whatever the duration and frequency of the exercise, **it takes time**.

CONFIDENCE IN THESE RESULTS:

⊕⊕⊕⊕ **High:** Further research is very unlikely to change our confidence in the estimate of effect.
⊕⊕⊕○ **Moderate:** Further research is likely to have an important impact on our confidence in the estimate of effect and may change the estimate.
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⊘ **Not evaluated** due to a lack of an estimate of effect.

Psychoeducation

Psychoeducation consists of programs to **teach caregivers the skills required in their caregiving role.** These programs **provide information about the health conditions of the person in their care**, and about the **resources and services available** to them. They also cover various topics, for example **behaviour or mood management skills, problem-solving, and environmental modification strategies.** Psychoeducation can be offered **individually over the phone or on the Internet, or in a group**.

BENEFITS

↓ Stress ⊕○○○

For every 100 older people who receive psychoeducation, **55** experience **reduced stress** due to psychoeducation.

↓ Depressive symptoms ⊕○○○

For every 100 caregivers who receive psychoeducation, **5** experience **reduced depressive symptoms** due to psychoeducation.

Well-being ⊕○○○

The current available research shows **no effect** of psychoeducation on caregiver well-being.

PRATICAL ISSUES

Time ⊘

Psychoeducation **takes time**. So far, the programs that have demonstrated positive impacts required **1-2 weekly sessions and lasted about 8 weeks.** Each session took **about one hour**.

May require travel ⊘

Group-based psychoeducation **may require caregivers to travel** to a location far from their home.

CONFIDENCE IN THESE RESULTS:

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OPTIONS
Explore the options

Support groups

Support groups are a **safe space to discuss issues related to caregiving, celebrate successes, and share strategies or ideas to help with the caregiver role**. There are various formats of support groups, including **face-to-face meetings, video or teleconferences, and online communities**. Support groups are often led by a person who shares, or has shared, the group's common experience, but they may also be led by a professional, such as a nurse, social worker, or psychologist.

BENEFITS

↓ Stress ⊕○○○

Caregivers who participate to a support group are **less likely to experience stress** than those who are not.

↑ Well-being ⊕○○○

For every 100 older people who participate in support groups, **6** experience **improved well-being** due to these groups.

Depressive symptoms ⊕○○○

The current available research shows no effect of participation in a support group **on caregiver's depressive symptoms**.

HARMS

↑ Discomfort in groups ⊕⊕○○

Some caregivers are **uncomfortable talking in large groups** of people.

PRATICAL ISSUES

↑ Challenges in attending meetings ⊕⊕○○

Some caregivers face **challenges** to attend support group meetings, such as:

- **not being able to leave the person in their care**
- the meeting taking place **too far away from their home**
- the meeting being held at **inconvenient meeting times**
- **not having any transportation**
- being **too busy**

CONFIDENCE IN THESE RESULTS:

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Respite care

Respite care consists of a wide range of services to **relieve caregivers of some of their duties**. It may be offered **in the home** by a professional or a volunteer who takes care of the care recipient for a while. It may also be offered **in an institution** that welcomes the care recipient and offers activities to entertain them. It can last anywhere **from a few hours to several days**.

BENEFITS

↓ Stress ⊕○○○

The current available research shows that respite care **does not reduce caregiver stress**.

↓ Depressive symptoms ⊕○○○

For every 100 caregivers who use respite care, **13** avoid **depressive symptoms** because of such care.

PRATICAL ISSUES

Access and costs

Respite services are not available everywhere. Most services also have costs (about $ 25 / hr).

HARMS

↑ Feelings of failure and guilt ⊘

Some caregivers find it difficult to give up their caring role.They may feel a sense of failure or guilt when they acknowledge a need for support, especially if they have negative perceptions of respite services. These negative attitudes may originate from their perceptions that the care staff may lack respect for their loved ones.

↑ Reluctance of care recipients ⊘

Some care recipients feel **reluctant** to use respite care. They can refuse to cooperate, causing more stress for the caregiver. This reluctance may stem from **their previous personality or social preferences**. Even with in-home respite care, some recipients may feel **uncomfortable with strangers**.

↑ Negative impacts on the care recipient ⊘

Respite care **may cause stress and confusion** in the care recipient. It may also lead to a **loss of mobility** when exercise is not maintained during respite, or a **loss of continence** due to more limited personal care. These impacts may in turn create more stress for the caregiver.

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Psychotherapy

Psychotherapy aims to improve an individual's well-being and mental health by having them **talk with a psychiatrist, psychologist, or other mental health provider**. During psychotherapy, you learn about your condition and your moods, feelings, thoughts, and behaviours. There are several different psychotherapy techniques. Psychotherapy may be delivered **in person** (one-on-one or with couples, or in groups), **over the phone, via telephone counseling, or via the Internet**.

BENEFITS

↓ Stress ⊕○○○

Caregivers who receive psychotherapy are **less likely to experience stress** than those who are not.

↓ Depressive symptoms ⊕○○○

Caregivers who receive psychotherapy are **less likely to experience depressive symptoms** than those who are not.

↑ Well-being ⊕○○○

For every 100 older people who receive psychotherapy, **4** experience **improved well-being** due to psychotherapy.

PRATICAL ISSUES

↓ Availability of psychotherapist ⊘

There are **wait lists** to consult a psychotherapist in the public sector. Psychotherapy is also offered in the private sector, at a **cost of about $100 per session**.

HARMS

Therapy discontinuation ⊕○○○

For every 100 persons who start psychotherapy, **20 quit** before the end due to **cost, lack of progress, dissatisfaction with therapy, anxiety during therapy, or because they moved to a different location**.

↑ Adverse effect ⊕○○○

For every 100 individuals who receive psychotherapy, **3 to 16** experience **adverse effects**, such as **negative emotions**, stigmatization*, **negative effects on their relationships**, **abuse** by the therapist.

Relapse ⊕○○○

For every 100 individuals who receive psychotherapy for 10-20 weeks, **27 relapse** within 1 to 2 years of the end of therapy.

* See Glossary p. 12

CONFIDENCE IN THESE RESULTS:

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Watchful waiting

Consists of **keeping an eye** on your stress levels **without undertaking treatment nor changing your lifestyle**.

BENEFITS

Avoid making a change if the impacts are uncertain ⊘

Among the caregivers who make changes to reduce their stress, a certain proportion **do not experience any improvement**. They may be **disappointed** that the steps they took did not allow them to reach their goals. Watchful waiting allows them to **avoid such disappointment**.

⇃ Downsides of interventions

All the available options to reduce caregiver stress cause some inconveniences. These inconveniences are reviewed in the previous pages of this document. People who do not undertake any new treatment or make changes to their lifestyle **will not experience any of these inconveniences**.

Take the time to find solutions yourself ⊘

Caregivers of seniors experiencing a loss of autonomy may wish to **take the time to find solutions by themselves**, and to try to develop strategies that best suit their needs, without pressure.

HARMS

⇑ Health problems ⊕○○○

Caregivers have 9% more chance of developing **health problems** compared to people who are not caregivers. Watchful waiting **increases one's risk of experiencing health problems**.

⇑ Mortality ⊘

Caregiving is associated **with increased mortality**. Watchful waiting thus **increases one's risk of death**.

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PRIORITIES

Limit your stress while respecting your priorities

SELECT WHAT IS MOST IMPORTANT TO YOU AND LOOK AT THE OPTIONS ASSOCIATED TO IT.*

✓ CHECK A SINGLE ITEM AT THE TIME

○ **Improve my well-being**

POSSIBLE OPTIONS TO LIMIT YOUR STRESS :

- Physical activity
- Support group
- Psychotherapy

○ **Reduce my symptoms of depression**

POSSIBLE OPTIONS TO LIMIT YOUR STRESS :

- Physical activity
- Psychoeducation
- Respite care
- Psychotherapy

○ **Avoid negative changes to my relationships with friends and family**

POSSIBLE OPTIONS TO LIMIT YOUR STRESS :

- Physical activity
- Respite care
- Case management
- Watchful waiting

○ **Avoid investing time to make a change**

POSSIBLE OPTIONS TO LIMIT YOUR STRESS :

- Watchful waiting
- Case management
- Respite care

○ **Other:** ____________________

List the options **to limit your stress** that support this priority:

____

____

○ **Avoid making a change if the impacts are uncertain**

POSSIBLE OPTIONS TO LIMIT YOUR STRESS :

- Watchful waiting

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* In this exercise, the benefits and harms of the available options (see previous pages) become priorities to consider. For example, if an option causes some harms, limiting these harms may be a priority for some people and they will want to consider other options.

CHOOSING AN OPTION

Which option do you prefer?

____

Are you comfortable with your choice?		**YES**	**NO**
SURE OF MYSELF	Do you feel SURE about the best choice for you?	○	○
UNDERSTAND INFORMATION	Do you know the benefits and risks of each option?	○	○
RISK-BENEFITS RATIO	Are you clear about which benefits and risks matter most to you?	○	○
ENCOURAGEMENT	Do you have enough support and advice to make a choice?	○	○

**IF YOU ANSWERED NO TO ANY OF THE QUESTIONS ABOVE,
TALK TO YOUR HEALTH PROFESSIONAL.**

SURE TEST

LIST OF CONTACTS TO ACCESS SERVICES

The *Caredove* website lists the available services in your region.

- Alberta: www.caredove.com/auaalberta
- Ontario: www.caredove.com/auawaterloowellington
- Quebec: www.caredove.com/auaquebec

GLOSSARY
Definitions

Stigmatization

If someone is stigmatized, they are unfairly regarded by many people as being bad or having something to be ashamed of. It may occur on the basis of physical appearance (including race or sex), of mental or physical illness, or of various other qualities.

CREDITS

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PATIENTS INCLUDED: Healthcare professionals, older adults, and friend or family caregivers participated in the design of this Decision box template, as study participants in research projects.

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NO CONFLICT OF INT EREST TO DECLARE:
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Physical Activity

Stress

Lambert et al. [2016]. Annals of Behavioral Medicine 50(6) : 907-919. Design : Systematic review of 14 studies, including 10 randomized control trials and 4 quasi-experimental designs ; 10 studies concerned the impact of physical activity on caregiver burden ; Participants : Depending on the study, 12-137 caregivers/study ; care recipients comprised patients with dementia, cancer, psychosis, stroke, or any disability or disease who were involved in studies concerning physical activity ; Intervention : A mix of physical activities including walking, yoga, meditation, aerobic exercise, tai chi, strength training, stretching, and/or lifestyle physical activities such as gardening, housework, stair climbing, and dancing. Activity duration ranged from 6 weeks to 12 months, and included those attending a weekly class as well as those who participated in daily exercise ; Follow-up : 3 to 12 months.

Depressive symptoms

Lambert et al. [2016]. Annals of Behavioral Medicine 50(6) : 907-919. Design : Systematic review of 14 studies, including 10 randomized control trials and 4 quasi-experimental designs ; 10 studies concerned the impact of physical activity on caregiver burden ; Participants : Depending on the study, 12-137 caregivers/study ; care recipients comprised patients with dementia, cancer, psychosis, stroke, or any disability or disease who were involved in studies concerning physical activity ; Intervention : A mix of physical activities including walking, yoga, meditation, aerobic exercise, tai chi, strength training, stretching, and/or lifestyle physical activities such as gardening, housework, stair climbing, and dancing. Activity duration ranged from 6 weeks to 12 months, and included those attending a weekly class as well as those who participated in daily exercise ; Follow-up : 3 to 12 months.

Well-being

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Sticking to the exercise program

Lambert et al. [2016]. Annals of Behavioral Medicine 50(6) : 907-919. Design : Systematic review of 14 studies, including 10 randomized control trials and 4 quasi-experimental designs ; 10 studies concerned the impact of physical activity on caregiver burden ; Participants : Depending on the study, 12-137 caregivers/study ; care recipients comprised patients with dementia, cancer, psychosis, stroke, or any disability or disease who were involved in studies concerning physical activity ; Intervention : A mix of physical activities including walking, yoga, meditation, aerobic exercise, tai chi, strength training, stretching, and/or lifestyle physical activities such as gardening, housework, stair climbing, and dancing. Activity duration ranged from 6 weeks to 12 months, and included those attending a weekly class as well as those who participated in daily exercise ; Follow-up : 3 to 12 months.

Injury

Hootman et al. [2002]. Med. Sci. Sports Exerc., Vol. 34, No. 5, pp. 838–844, 2002. Design : Aerobics Center Longitudinal Study (ACLS), a prospective study of the health effects of physical activity and fitness at the Cooper Clinic ; Participants : 5,028 men and 1,283 women aged 20–85 who were enrolled in the study between 1970 and 1982 ; Intervention : Physical activity (run/walk/jog or strenuous sports program). Follow-up : 12 months.

Psychoeducation

Stress

New meta-analysis by the Decision Box team based on the results reported in Sorensen et al. [2002]. Gerontologist 42(3) : 356-372. Design : Meta-analysis of 13 RCTs concerning psychoeducation ; Participants : 732 seniors with physical disabilities or mental illness, stroke patients, cancer patients, and dementia patients ; Intervention : Psychoeducation ; Follow-up : Immediate post-treatment to 12 months after treatment.

Depressive symptoms

New meta-analysis by the Decision Box team based on the results reported in Sorensen et al. [2002]. Gerontologist 42(3): 356-372. Design : Meta-analysis of 10 RCTs concerning psychoeducation ; Participants : 607 seniors with physical disabilities or mental illness, stroke patients, cancer patients, and dementia patients ; Intervention : Psychoeducation ; Follow-up : Immediate post-treatment to 12 months after treatment.

Well-being

Sorensen et al. [2002]. Gerontologist 42(3): 356-372. Design : Meta-analysis of 78 studies, including randomized control trials and other study designs, where an intervention condition was compared with an untreated control condition ; 10 studies concerned psychoeducation, including 3 randomized control trials ; Participants : Depending on the study, from 4 to 2,268 caregivers/study (median of 24); care recipients comprised patients with physical disabilities or mental illness, stroke patients, cancer patients, and dementia patients ; Intervention : Multiple interventions, including psychoeducation, support groups, and psychotherapy ; Follow-up : Immediate post-treatment.

Time

Sorensen et al. [2002]. Gerontologist 42(3): 356-372. Design : Meta-analysis of 78 studies, including randomized control trials and other study designs, where an intervention condition was compared with an untreated control condition ; 10 studies concerned psychoeducation, including 3 randomized control trials ; Participants : Depending on the study, from 4 to 2,268 caregivers/study (median of 24); care recipients comprised patients with physical disabilities or mental illness, stroke patients, cancer patients, and dementia patients ; Intervention : Multiple interventions, including psychoeducation, support groups, and psychotherapy ; Follow-up : Immediate post-treatment.

Support groups

Stress

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Well-being

New meta-analysis by the Decision Box team based on the systematic review results reported in Sorensen et al. [2002]. Gerontologist 42(3): 356-372. After careful examination of the review results, we could use only one of the studies cited in the review to estimate absolute risks in each experimental group, as the other included studies did not present any variability results. The results were thus extracted from Quayhagen et al. [2000]. International Psychogeriatrics, 12, 249–265. Design : Randomized controlled trial ; Participants : Sample size from 37 caregivers of seniors with dementia ; Intervention : Support groups ; Follow-up : 3 months.

Discomfort in groups

Gage & Kinney. [1995]. Clinical Gerontologist 16 : 21-34. Design : Retrospective cohort study ; Participants : 27 caregivers of seniors living with dementia who attended a support group, and 52 who did not attend ; Intervention : Support group attendance ; Follow-up : Direct measure.

Challenges in attending meetings

Gage & Kinney. [1995]. Clinical Gerontologist 16 : 21-34. Design : Retrospective cohort study ; Participants : 27 caregivers of seniors living with dementia who attended a support group, and 52 who did not attend ; Intervention : Support group attendance ; Follow-up : Direct measure.

Respite care

Stress

Mason et al. [2007]. J Am Geriatr Soc 55(2): 290-299. Design : Meta-analysis of 9 studies, including 5 randomized control trials and 4 quasi-experimental designs ; 8 studies concerned respite care, including 4 randomized control trials and 4 quasi-experimental designs ; Participants : Depending on the study, 21-989 caregivers/study ; care recipients comprised patients with dementia or frailty ; Intervention : Mix of daycare, in-home respite, and respite packages ranging from 10 days over a 2 week-period to 12 months, at a frequency of 1 to 5 times a week ; Follow-up : Immediate post-treatment.

Depressive symptoms

Transformation to absolute risks by the Decision Box team of data reported in Mason et al. [2007]. J Am Geriatr Soc 55(2): 290-299. Design : Meta-analysis of 9 studies, including 5 randomized control trials and 4 quasi-experimental designs ; 3 studies concerned respite care including 1 randomized control trial and 3 quasi-experimental designs ; Participants : Depending on the study, 21-989 caregivers/study ; care recipients comprised patients with dementia or frailty ; Intervention : Mix of daycare, in-home respite, and respite packages ranging from 10 days over a 2-week period to 12 months, at a frequency of 1 to 5 times a week ; Follow-up : Immediate post-treatment.

Feelings of failure and guilt

Shaw et al. [2009]. Health technol Assess ; 13(20):1-224. Design : Qualitative synthesis of 70 primary studies ; Participants : Caregivers of people aged 65 or more ; Intervention : Respite interventions designed to provide the caregiver with a break from caring.

Reluctance of care recipients

Shaw et al. [2009]. Health technol Assess ; 13(20):1-224. Design : Qualitative synthesis of 70 primary studies ; Participants : Caregivers of people aged 65 or more ; Intervention : Respite interventions designed to provide the caregiver with a break from caring.

Negative impacts on the care recipient

Shaw et al. [2009]. Health technol Assess ; 13(20) : 1-224. Design : Qualitative synthesis of 70 primary studies ; Participants : Caregivers of people aged 65 or more ; Intervention : Respite interventions designed to provide the caregiver with a break from caring.

Psychotherapy

Stress

Sorensen et al. [2002]. Gerontologist 42(3): 356-372. Design : Meta-analysis of 78 studies, including randomized control trials and other study designs, where an intervention condition was compared with an untreated control condition ; 10 studies concerned psychoeducation, including 3 randomized control trials ; Participants : Depending on the study, from 4 to 2,268 caregivers/study (median of 24); care recipients comprised patients with physical disabilities or mental illness, stroke patients, cancer patients, and dementia patients ; Intervention : Multiple interventions, including psychoeducation, support groups, and psychotherapy ; Follow-up : Immediate post-treatment.

Depressive symptoms

Sorensen et al. [2002]. Gerontologist 42(3): 356-372. Design : Meta-analysis of 78 studies, including randomized control trials and other study designs, where an intervention condition was compared with an untreated control condition ; 10 studies concerned psychoeducation, including 3 randomized control trials ; Participants : Depending on the study, from 4 to 2,268 caregivers/study (median of 24); care recipients comprised patients with physical disabilities or mental illness, stroke patients, cancer patients, and dementia patients ; Intervention : Multiple interventions, including psychoeducation, support groups, and psychotherapy ; Follow-up : Immediate post-treatment.

Well-being

New meta-analysis by the Decision Box team based on the results reported in Sorensen et al. [2002]. Gerontologist 42(3) : 356-372. Design : Meta-analysis of 2 studies where psychotherapy was compared to an untreated control condition ; Participants : 56 caregivers of seniors with physical disabilities or mental illness, stroke patients, cancer patients, and dementia patients ; Intervention : Psychotherapy ; Follow-up : 3 to 12 months.

Therapy discontinuation

Swift & Greenberg. [2012]. J Consult Clin Psychol, 80(4), 547-559. Design : Systematic review of 669 studies ; Participants : 83,834 adults who engaged in psychological or psychosocial intervention ; Intervention : Psychological or psychosocial intervention.

Adverse effect

Ladwig et al. [2014] Verhaltenstherapie, 24(4), 252-263. Design : Cross-sectional online survey ; Participants : 195 adults who consulted for depressive, anxiety, personality, food, or other disorders, or schizophrenia ; Intervention : Psychotherapy.

Relapse

De Maat et al. [2006]. Psychother. Res., 16(5), 566-578. Design : Systematic review of 10 randomized controlled trials ; Participants : 1,233 adults (19-65 years old) with major depression ; Intervention : Psychotherapy, compared to pharmacotherapy. Length of intervention : 10-20 weeks for pharmacotherapy or 8-20 weeks for psychotherapy ; Follow-up : 1-2 years.

Watchful waiting

Health problems

Vitaliano et al. [2003]. Psychol Bull 129(6) : 946-972. Design : Meta-analysis of 23 samples reported in 45 quasi-experimental studies ; Participants : Sample size of 3,029 caregivers of patients with dementia, and non caregivers.

All causes of death

Perkins et al. [2013]. J Gerontol B Psychol Sci Soc Sci 68(4) : 504-512. Design : Longitudinal study ; Participants : 3,647 caregivers ; Intervention : no intervention ; Follow-up duration : every 6 months.