

How can we best support those who care?

Research Paper Series: Summary Report

This Summary Report provides a snapshot of the outcomes from a partnership between **Everymind** and *beyondblue*: the national depression initiative, to extend what is known and understood about how best to support people in Australia who love and care for someone with depression.



“It’s not just coping on your own, you’re both fighting this... you’re both in this together.”



About the Paper Series

Depression affects one million Australians every year, and it is estimated that up to 20% of Australians will experience depressive symptoms at some stage in their life¹. Depression is the leading cause of non-fatal disability in Australia² and is predicted to be the world's biggest health problem by 2020³.

Family and friends of people with depression provide the majority of practical and emotional support. They face many challenges. While there is increasing recognition of the importance of supporting family and carers of people with mental illness, there has been much less focus on the experience of people who love, support and care for someone specifically experiencing depression.

From 2011-2012, Everymind (formerly the Hunter Institute of Mental Health) and *beyondblue*: the national depression initiative agreed to partner and co-fund the development of a series of reports that would result in better understanding about the role of, and how best to support, those who care for a person with depression.

Using national data being collected for *Partners in Depression*, a series of six studies relevant to this target group was actioned. The report series is summarised in this document for immediate dissemination. Full research analysis and outcomes will be published in peer-review journals to progress the national and international evidence-base.

This is an important series of studies that combined provide a range of practice implications for Australia.

We hope these outcomes can be used to better inform national approaches to support those who love, live with or care for people with depression.



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The research paper series includes:

Study 1

Systematic review of the literature regarding the effectiveness of interventions for carers of people with depression.

Study 2

Coping with caring for a person with depression.

Study 3

Australian clinicians' attitudes, clinical practices, and barriers to providing carer inclusive practice for those supporting a person with depression.

Study 4

Predictors of mental health in Australian carers of people with depression.

Study 5

Impact of the *Partners in Depression* program.

Study 6

Effectiveness of the dissemination strategy used for the national roll-out of the *Partners in Depression* program.



Summary and Recommendations

The following eight conclusions and recommendations have been developed based on review of the findings across the report series.

1. People who love, live with or care for someone experiencing depression are vulnerable to poor mental health, frequently to a level indicative of requiring specific therapeutic support themselves.

2. There are a significant number of people who care for someone with depression who are seeking help, support or more information to help them manage their role. It is important that people are provided with timely and ongoing access to appropriate, relevant and effective interventions to reduce carer burn out, increase resilience and improve outcomes for carers and the people they support.

Families, carers and friends are the largest providers of care and support for people living with depression in Australia.

But few mental health services specifically target the information or support needs of people who love or care for someone with depression.

3. Interventions targeting those who love, live with or care for someone with depression should include provision of information about depression (e.g. causes, treatments, outcomes) and issues related to the caring role (e.g. ways to provide support, responding to a crisis, coping strategies, self-care) and relevant skill building.

It may also be helpful if interventions address:

- Ways of dealing with objective (or practical) carer burden. For example, managing increased responsibilities, how to 'share' the load;
- Coping strategies - including ways to reduce the use of these strategies that rely on avoidance and self-blame, and increase the use of strategies that incorporate acceptance and reframing;
- Communication styles and ways to strengthen the relationship between the carer and the person with depression;
- Hope for the future, including how to maintain a sense of control, regardless of the recovery stage of the person being supported.

4. Group education programs, such as *Partners in Depression*, can be an appropriate intervention to offer people who care for someone with depression, particularly if they identify an interest in connecting with others.

The *Partners in Depression* group education program specifically appears to meet the information and support needs of Australian people who love, live with or care for someone with depression and program attendance was associated with a significant decrease in levels of psychological distress. These results are promising and a study using a control comparison group is needed as a matter of urgency to confirm that the benefits reported by participants are a consequence of program attendance rather than some other factor.

5. There are a number of barriers for mental health service providers in delivering support to people who love, live with or care for someone with depression.

To improve capacity for carer inclusive practice, it would appear likely that specific supports and processes will be required to enable clinicians to routinely provide psycho-educational information about depression to support people.

Capacity to provide specific carer support appears to be enhanced when carer support is considered part of 'core business'.

However, even when carer support is not considered core business, it would be appropriate for mental health and primary care service providers to, as part of routine practice, identify whether the carer is experiencing psychological distress, needs further support and assist them in accessing that support.

6. Stronger collaboration and partnership between mental health services and carer support services may assist in increasing the level of support provided to those who love, live with or care for someone with depression.

This could be addressed by identifying opportunities for these groups to work together (e.g. delivering a group education program together) and through establishing or utilising existing service provider peer networks to assist in up-skilling and supporting frontline providers to respond to the needs of carers of people with mental illness.

It would also be appropriate to ensure that service providers have ready access to relevant information and resources about supporting those who care for someone with depression specifically. This may include developing guidelines or professional development resources about family and carer inclusive practice for people with depression and establishing an electronic hub or clearinghouse of material, literature and evidence summaries relevant to supporting this target group.

7. Many people who provide care and support for people with depression do not self-identify as a 'carer' and remain 'hidden'.

A comprehensive community awareness campaign and 'call to action' would help people in the support role to identify if they required assistance and the types of supports that are available.

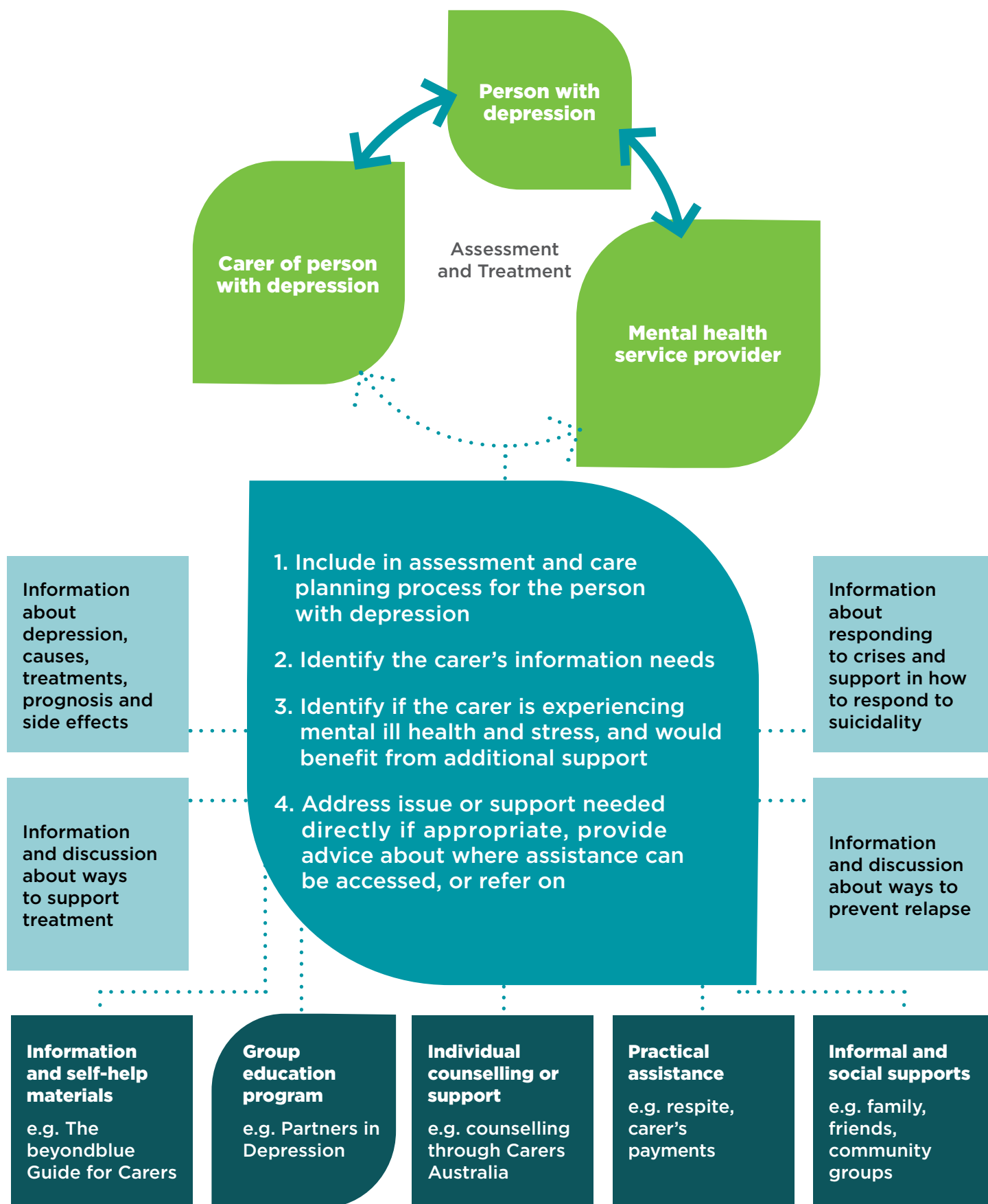
This would also increase health and community workers' awareness of the existence and needs of people who love, live with or care for someone with depression and help service providers wishing to provide support connect more easily to this target group.

8. An ongoing research program investigating the effectiveness of supports for carers of people with depression is needed.

Studies are required that use before-after designs, control comparison groups, standardised measures, longer follow up periods, and which capture outcomes for carers, the person with depression and those who 'drop out'.

Further exploration is needed to establish the relevance and effectiveness of interventions for different population groups (e.g. Aboriginal and Torres Strait Islander families, culturally and linguistically diverse families, young people in a caring role and those who identify as Lesbian, Gay, Bisexual, Transgender, or Intersex). More exploration of different settings is also needed.

A model for supporting those who love, live with or care for someone with depression



Summary of Study 1

Systematic scoping review of the literature regarding the effectiveness of interventions for carers of people with depression

Background

Family members and carers of people with depression are vulnerable to poor mental health as a result of the carer role^{4 5 6}. There is also evidence to suggest that the nature of the relationship a person with depression has with their primary supports (e.g. family members or partners) impacts on or predicts recovery and relapse rates⁷. However, there have been no systematic reviews of the effectiveness of interventions for people who care for or support a person with depression.

What did we do?

Due to the limited number of studies conducted that are relevant to this target group, a systematic scoping approach was taken. The aim of the review was to identify the types of interventions that have been developed to address the needs of carers of people with depression and the relative impact of these interventions on carers' mental health and wellbeing. Five electronic databases and a scan of the grey literature using Google and Google Scholar were searched using the key terms 'caregiver', 'carer' and 'family' in combination with 'intervention', 'family intervention', 'psycho-education', 'program evaluation', 'program' and 'therapy'. Two project team members independently screened the article titles. Abstracts or full articles were retrieved when there was an indication that the study described the effectiveness of an intervention for carers of people with depression.

Outcomes

The search strategy resulted in 3557 'hits'. Of these, 13 relevant studies (including 8 full text articles and 5 abstracts [articles only available in German]) were identified. An additional 12 articles were identified as relevant (that is, they described a carer intervention and included carers of people with depression as participants) but did not describe outcomes for the carer participants. All of the interventions described in the studies were psycho-educational in nature and focused either on providing information about depression, its treatment and service availability or providing information designed to increase the carers' coping and stress management skills.

The type of outcomes measured varied. While there were too few studies to conclusively say that the carer interventions positively benefited the carers with regard to their mental health and wellbeing, those studies that used before-after designs usually showed positive effects.

Implications

As there is relatively little known about the effectiveness of interventions for people who love, live with or care for someone with depression, further research is needed. Specifically, research that investigates the impact of interventions for those who support a person with depression using before-after designs, comparison groups, standardised outcome measures and adequate follow up periods is needed.

For mental health clinicians, this review highlights the importance of considering the needs of the carer not just because of their potential role in supporting the recovery of the person with depression, but also because they may benefit directly from carer specific support.

Summary of Study 2

Coping with caring for a person with depression

Background

Qualitative studies have previously explored what the carer journey is like for those who support a person with mental illness, including depression^{8,9,10}. Participants in these studies describe a process of change and adaptation and a variety of challenges which they face as a result of providing care and support. Whilst partners are frequently the primary providers of support to people with depression, only a few studies have investigated the specific experience of partners. Furthermore, to date, studies have not specifically investigated how carers of people with depression explain how they have coped with the challenges posed by the support role.

What did we do?

Eight partners of people with depression were interviewed about how they had coped with the carer role. Participants were recruited through promotional notices in health service waiting rooms, support group venues and on public information boards (e.g. university, health service) and through verbal information provided to people attending *Partners in Depression* programs in the Hunter region. The data collected was analysed using an interpretative phenomenological analysis approach.

Outcomes

Six key themes emerged regarding how participants reported having coped with providing care and support to their partner.

The themes included:

- 1. Working out how to make sense of it all.** Participants spoke about seeking information to gain a better understanding of the depression. This understanding often enabled them to more easily provide support to their partner.
- 2. Working out when to take or relinquish 'control'.** Participants spoke about learning which areas of their life meant taking on more responsibility (or 'control'), was helpful for them (e.g. household activities, financial responsibility, looking after their own needs), and which ones were better if they took a 'step back' (e.g. trying to make their partner seek treatment). Trying to take responsibility for things out of their control led to increased frustration and distress.
- 3. Redevelopment of their relationship with their partner.** Participants identified changes in their relationship with their partner that had occurred as a result of the depression, and how changes in communication, expectations and attitudes provided a foundation for being able to stay in a meaningful relationship.
- 4. Development of a united front with their partner.** Participants spoke about the development of a sense of a shared journey and that they were 'fighting the battle together'. This gave them a way of providing stability within the relationship that was independent of their partner's wellness.
- 5. Learning to look after themselves as well.** Participants spoke of the importance of self-care in coping with the carer role. This included working out ways of expressing their emotions, keeping social connections, looking after their physical health, having time away from the depression and seeking support for themselves.
- 6. Looking to the future.** Participants all spoke about their expectations for the future. Some were hopeful about a happy future where the depression was improved or the person was completely recovered, others saw 'more of the same'. Looking forward seemed to provide participants perspective, helping them to work out what was important to focus on now.

Implications

This study provides a map of the issues that are likely to arise for partners of people with depression as they provide support to the person they share their life with. It is important that information, interventions and support provided to partners of people with depression have the capacity to respond to these issues and do so in such a way that they seek to build on, and strengthen, existing narratives of coping.

Summary of Study 3

Australian clinicians' attitudes, clinical practices, and barriers to providing carer inclusive practice for those supporting a person with depression

Background

Government policies at federal and state level commit mental health services to involving carers in the delivery of services. However, despite significant evidence as to the benefits of carer inclusive practice for people with mental illness, carers frequently report feeling disengaged from the mental health care provided to the person they support and isolated in managing the struggles posed by the caring role^{11,12}. The latest Mental Health Carers' Report¹³ suggested that while there appear to be improvements in the rate of inclusive practice, it remains "patchy".

Some qualitative studies have explored what impacts on clinicians' capacity to engage in carer inclusive practice^{14,15}. No studies thus far have looked at what influences the support provided to Australian carers of people with depression from the perspective of clinicians.

What did we do?

A total of 119 Australian mental health clinicians were surveyed with a self-report questionnaire to gather information on their attitudes, clinical practices, and perceived barriers to engaging in carer inclusive practice for people with depression.

The sample included clinicians whose primary client group included mental health consumers, and clinicians whose primary clients were family members and carers. Multiple recruitment strategies were used, including promotion of the study on the **Everymind** website and through local heads of disciplines, professional associations and service managers; as well as inviting all clinicians who attended the *Partners in Depression* facilitator training between March 2010 and April 2011.

Outcomes

Participants generally reported positive attitudes regarding the value and importance of involving family members and carers in the assessment and treatment process for people with depression. However, even amongst this self-selecting sample, there was room for significant improvement in the rates of carer inclusive practice.

Over half (55%) reported only involving a family member or carer in the assessment and treatment process for a person with depression infrequently ('sometimes', 'rarely' or 'never'). Participants identified many barriers to inclusive care, with the most frequent being organisational in nature (e.g. not within service scope, lack of agency support to provide services for carers and too many other demands from workload to work with carers of people with depression).

This study suggests there is a good foundation for provision of support to family members and carers of people with depression, which could be enhanced through additional capacity.

In short, despite positive attitudes, carer inclusive care did not appear to be routine practice and clinicians identified numerous barriers in delivering carer inclusive supports.



Implications

This study suggests that carer inclusive practice for people with depression is not yet the norm. However, we need to identify the degree to which the practice and perceptions of this self-selecting sample is representative of general mental health service clinicians. A study using non self-selecting recruitment strategies, audit methodology or measures specific to the Australian context would be useful.

There is a need to identify not only what is hindering carer inclusive practice, but also what enables it.

Findings from this study are consistent with others that suggest that organisational barriers significantly impact on clinicians' capacity to engage in carer inclusive practice^{16 17}. Ways of overcoming these barriers need to be investigated and may involve looking at how carer inclusive practice can be prioritised in service delivery, how service models have become family inclusive or if the needs of carers can be best addressed by having good collaborative and seamless ties across services (and sectors).

It may be relevant to identify a range of 'best' or effective innovative case studies to identify the ways in which barriers to carer inclusive support have been overcome.

Jenice's story...

As a Mental Health Promotion Co-ordinator I take an active role in raising awareness of, and promoting, positive mental health in our community. I work in collaboration with other health workers and service providers.

Partners in Depression offered an evidence-based program to specifically support families, friends and carers of our clients experiencing depression. The content and resources are excellent and the facilitators are so well supported by the *Partners in Depression* team.

Participants coming into the program gain so much. They have an opportunity to share their personal stories and experiences which they find extremely useful.

To realise you are not alone and others are going through a similar experience is very powerful. Participants also gain practical skills such as communication and how to implement self-care strategies into their busy lives.

When you see someone in the program "get it" – whatever "it" is for them – is the most memorable part of the program for me as a facilitator.

When participants complete the *Partners in Depression* groups, we see them with a greater sense of hope for the future and an improved understanding of the impact depression is having on their family member or friend.

Summary of Study 4

Predictors of mental health and wellbeing in Australian carers of people with depression

Background

As a group, carers are consistently found to experience higher rates of mental ill-health than the general population¹⁸¹⁹. However, not all carers are impacted by the carer role to the same degree or in the same way. Whilst qualitative studies have been conducted with Australian carers of people with depression about their wellbeing, no quantitative studies have targeted this specific group of carers in Australia. Further, few studies have investigated the relationship between mental health, caregiver burden, coping strategies and social support amongst carers of people with depression.

What did we do?

A total of 159 carers of people with depression completed a self-report questionnaire comprising standardised and specifically developed scales that covered information about the characteristics of their carer role, caregiver burden, the positive growth they had experienced from the carer role, coping strategies, social support and their mental health. Participants were recruited through a variety of agencies in contact with carers across Australia (e.g. *beyondblue*, carer support services, attendees at the *Partners in Depression* program), who provided information about the study to relevant service users.

Outcomes


In this service-using sample, nearly half of the participants reported some psychological distress and they were 2.75 times more likely to report severe psychological distress than the general population (as measured by the Kessler-10).

The most important predictor of their mental health and wellbeing was the level of objective burden. The use of unhelpful active coping strategies (venting, instrumental support, self-blame), and to a lesser degree, the unpredictability of the depression, also contributed to their mental health status.

Implications

This study indicates that carers of people with depression are particularly vulnerable to compromised mental health and wellbeing when they are required to provide a lot of practical support and engage in unhelpful coping strategies. It would seem important to ensure that this group of carers are identified early in their caring journey, and put in touch with services and supports that can reduce the demands on them or which can improve the fit between the coping strategies they use and the demands placed on them.

**“Are we going to have a good day? Are we going to have a bad day? . . .
At times you’re walking on eggshells.”**



Summary of Study 5

Impact of the Partners in Depression program

Background

Carers of people with depression are consistently found to experience higher rates of mental ill-health compared to the general population^{20 21}. There is increasing evidence to suggest that providing carer supports as part of the treatment for a person with depression^{22 23 24} is associated with recovery benefits for the person with depression.

Studies that have specifically investigated the benefits of a carer intervention for the person providing care and support usually identify improvements in carer mental health and wellbeing post-intervention. However, these studies have usually been small in sample size, conducted overseas or without a follow up assessment^{25 26 27 28}.

This study investigated the impact of *Partners in Depression* as delivered through the National Dissemination of the program. The *Partners in Depression* program is a group education course for people who support a person with depression. It is delivered by two local health or community professionals who received specific training by **Everymind**. The program has a dual focus by providing information relevant to supporting a person with depression and opportunities to reflect on the carer experience.

The program is conducted over 6 weekly sessions of 1-2 hours, delivered by local facilitators across Australia
www.partnersindepression.com.au

***Partners in Depression* is an education and support program for families and friends who love, live with or support a person experiencing depression.**

What did we do?

People who attended the *Partners in Depression* program between March 2010 and April 2012 were invited to complete a questionnaire before and after the program to help evaluate the effectiveness of the intervention. The questionnaire collected information about participant demographics, characteristics of the person being supported, the mental health of participants (using the Kessler 10), questions about mental health promoting attitudes and behaviours targeted by the program and program feedback questions.

Outcomes

In total, 958 people completed the baseline and post-program questionnaire and 118 people completed the six month follow up questionnaire; of these, 664 and 42 responses could be matched with a baseline response respectively. Post-program responses indicated that participants were highly satisfied with program content and delivery, and that they reported a significant reduction in level of psychological distress and significant increases in ratings of importance, or engagement in, mental health promoting attitudes and behaviours specifically targeted by the program.

Implications

The *Partners in Depression* program appears to be an appropriate intervention to offer people who love, live with or care for someone with depression across Australia. Given the positive outcomes for participants, it would be appropriate to ensure that the program remains accessible to this population group.

A randomised controlled trial or, at a minimum, a study with a waiting list control group, is needed to establish that the mental health benefits reported by program attendees are due to program attendance rather than other factors. The evidence would also be strengthened by using additional standardised measures of expected outcomes (e.g. coping strategies).

The relevance of the program for specific subpopulations (e.g. younger people, different cultural groups, men) should be further investigated and it may be appropriate to develop and pilot program adaptations.

It would be useful to identify the benefits of this program compared to other carer supports or interventions to identify the most meaningful and cost effective way of supporting this population group.



Kim's story...

I have officially been supporting my wife for the past seven years, but I know I've been a carer for a lot longer than that. It was a major concern that there was something wrong, but you can't always put a name to it straight away.

I don't think this is a situation where you can say it's sorted, because it changes all the time. You have to adapt to the mood swings, and as she gets better or gets sick you have to adapt to that too.

One of the things I've always had in my mind and I said from the start, "I'm not going anywhere". And I keep saying to my wife "our relationship will not end and I will not be leaving". It's what she needs to know because sometimes she doesn't know what is going to happen next, and she needs to know I'm there to back her up. I hope that makes it a little easier for her.

Attending the *Partners in Depression* group made a huge difference. Knowing you aren't alone and connecting with people who can say "I know you're having the same problem as I'm having. It can be dealt with". It halves the worry and breaks it down.

The more information you've got, the more you can talk about it, and the more things come out – stuff that would never have come out in the first place.

Summary of Study 6

Effectiveness of the dissemination strategy used for the national roll-out of the *Partners in Depression* program

Background

There are many challenges in making helpful interventions available on a broad scale, particularly when they require practitioners to change the way they usually practice. General dissemination literature highlights the importance of effective training, perceived value of the intervention, good and easy fit with the practice setting and proactive technical program support and advice²⁹³⁰. However, it is not known the degree to which these factors play a specific role in how Australian service providers may be engaged in delivering a new intervention that specifically targets carers of people with depression.



What did we do?

The data collected through the national dissemination of the *Partners in Depression* program was used to investigate the impact of dissemination process factors (e.g. stakeholder engagement, training, technical assistance provided), individual facilitator characteristics (e.g. sector, role, location) and perceived barriers on facilitator delivery of the program in their local community.

Program data was reviewed from 427 service providers who completed the *Partners in Depression* facilitator training between March 2010 and April 2011. This included information about level of stakeholder engagement, facilitator training course feedback, facilitator demographic information, level of project support provided, facilitator post program feedback and number of planned, cancelled and actual delivered programs.

Outcomes

A total of 211 *Partners in Depression* groups were delivered during the timeframe of interest, resulting in over 1120 people attending the program across Australia.

Of the 427 facilitators trained, only 44% actually delivered a group. The facilitators most likely to deliver a program were those for whom delivering a carer/family or mental health group education program could be considered core business. State residence also had a significant impact, although it is unclear what this variable specifically captured (e.g. state level infrastructure, impact of natural disasters in particular geographical states, etc). Level of proactive support from the project team did not appear to assist facilitators move from the planning to implementation stage and there were many barriers to program delivery, including difficulties in recruitment of the target group.

Implications

The findings from this study suggest that the most efficient way of disseminating an intervention that targets carers of people with depression is to specifically engage service providers for whom program delivery could be considered core business (although this limits the opportunity to change routine practice of general mental health service providers).

It also highlights the potential importance of establishing local peer network implementation groups, utilising existing infrastructure to support and coordinate local program delivery and identifying ways to maintain initial enthusiasm and commitment to program delivery.

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www.everymind.org.au/partners-in-depression



Everymind

Everymind was established locally in Newcastle NSW in 1992 and has been delivering best-practice mental health and suicide prevention programs for over 25 years.

Everymind is supported by a diverse and passionate team who are dedicated to the prevention of mental ill-health, the prevention of suicide and the promotion of mental health and wellbeing.

Key Objectives:

1. Improve the mental health of individuals and communities;
2. Reduce the incidence, prevalence and impact of mental health problems and mental illnesses;
3. Reduce the incidence of suicide, the prevalence of suicidal behaviours and their impact;
4. Build the evidence for promotion and prevention approaches in mental health and suicide prevention;
5. Build organisational strength, reputation and sustainability.

Everymind acknowledges Aboriginal and Torres Strait Islander people as the traditional owners of the land, and that we live and work on Aboriginal and Torres Strait Islander land.

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beyondblue: the national depression initiative

beyondblue works to address issues associated with depression and anxiety in Australia and is a national, independent, not-for-profit organisation.

beyondblue's key aims are raising awareness about depression and anxiety, reducing associated stigma and encouraging people to seek help early. *beyondblue* works in partnership with health services, schools, workplaces, universities, the media and community organisations, as well as people living with depression and/or anxiety and those who care for them, to bring together their expertise for the benefit of all Australians.

To find out more visit www.beyondblue.org.au or call the Support line on 1300 22 4636 (available 24 hours a day, 7 days a week).



Partners in Depression

Partners in Depression is a **cost-effective** and **evidence-based** education and support program for families, carers and friends who love, live with or support a person experiencing depression.

The program was developed by **Everymind** (formerly the Hunter Institute of Mental Health) and is delivered to families, friends and carers by program partners working in community based mental health services across Australia. Partner organisations are provided with extensive workforce development, clinical and implementation support and to ensure maximum benefit from program participants across Australia.

The National Evaluation of *Partners in Depression* indicates that the program **improves the mental health, wellbeing, help seeking behaviours, relationships and social participation of families and carers.**

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