

EXPLANATORY STATEMENT**People with mild dementia/cognitive impairment****Project ID: 39672****Project title: Changing the focus: Facilitating engagement in physical activity for people with dementia in a local community - A feasibility study****Chief investigator: Prof Keith Hill**Rehabilitation, Ageing and Independent Living Research Centre, Monash University
email: keith.hill@monash.edu**Project manager: Dr Angel Lee**Rehabilitation, Ageing and Independent Living Research Centre, Monash University
email: angel.lee@monash.edu

You are invited to take part in this study. Please read this Explanatory Statement before deciding whether or not to participate in this research. If you would like further information regarding any part of this project, you can contact the researchers via email addresses listed above.

What does the research involve?

The purposes of the study are to:

- Run the “Changing the Focus” physical activity program (see below for a description of what the program involves)
- Evaluate program, health and wellbeing outcomes for people with mild dementia/cognitive impairment and estimate health care and “Changing the Focus” program costs.

The “Changing the Focus” program is a 12-month personalised physical activity program. The program may consist of local community exercise programs, home-based exercises or a combination of these. People living with mild dementia or cognitive impairment who live in Frankston/Mornington Peninsula will be invited to take part.

Before the program begins, a study therapist will:

- Visit you (and your carer if applicable) at your home to complete the consent forms, collect information about yourself (and your carer if applicable) and perform some tests to assess your physical health and wellbeing. This may take about 2.5 hours with a rest break.
- Discuss physical activity options and set personalised goals.
- Teach you (and your carer if applicable) how to fill in a falls and exercise diary.

During the 12-month program, you will:

- Attend the chosen physical activity program(s) within 2 weeks from the first home visit.
- Complete your falls and exercise diary every [week](#).
- Take part in 3 more home visits by the therapist (at week 3, month 6 and 12). This may take about 1 hour each visit. The study therapist will discuss your involvement in the program and provide support for ongoing involvement.
- Take part in re-assessments for your physical health and wellbeing (at month 6 and 12 visits only).
- Take [7](#) calls from the study therapist to provide support for your ongoing involvement in the program. The calls will be spread out over [the first 6](#) months and take about 20 minutes each call.
- Provide your exercise and falls diary at each visit and support call to the study therapist.

Additional home visits and phone calls can be arranged if you require extra support.

Why are you invited for this research?

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You are invited to participate in this study because your health professional, case manager, family member or friend has referred you to the program or you have seen the advertisement and decide to take part.

Source of funding

This research is funded by the National Centre for Healthy Ageing, Monash University.

Consenting to participate in the project and withdrawing from the research

Being part of this study is voluntary. Signing the consent form indicates you have given informed consent to take part in the program and evaluations, and agree to the use of your data for evaluating the program. You may withdraw from the study at any time by notifying the study therapist or project manager as soon as possible. There will be no follow-up by the research team or the referrer (if this applies to you) if you withdraw. The information already collected from you will be used to evaluate the program and cannot be withdrawn.

Possible benefits and risks to participants

You may experience benefits from regular exercise including improved physical activity level, physical function and quality of life.

There can be a risk of falls in people with mild dementia or cognitive impairment when exercising. Research shows that taking part in health professional prescribed exercise programs can be safe and feasible. Falls risk will be minimised through supervision of exercises by the physical activity provider and/or the carer during the program. The research team will provide training and resources to ensure safety during exercise. You will also be supported by the study therapist with regular contacts.

Services on offer if adversely affected

While we will make every effort to prevent a fall, it can happen. If you fall during the physical activity program, the exercise provider will follow their organisation’s policy and notify your family. The exercise provider will report the incident to the research team. The research team will work with the exercise provider, you, your carer (and your medical practitioner if applicable) to decide whether your continuing in this study is appropriate.

In the case of a fall or an adverse event during home exercise (for those where this is provided), you and/or your carer should seek medical help from your medical practitioner. You and /or your carer will be asked not to continue with the home exercises until the chief investigator/project manager or study therapist reviews or modifies the program.

If you require counselling, you can call the National Dementia Helpline on [1800 100 500](tel:1800100500). The researcher will be able to help with this process or you can visit your GP for more advice.

Payment

There is no payment for taking part in the physical activity program. Depending on the chosen physical activity program(s), you may need to pay a low cost in order to attend the program(s) and meet the associated transportation cost for the 12-months’ duration.

Confidentiality

Any information obtained in the study that may identify you and/or your carer will be de-identified at the completion of the study. The interview audio recording will be transcribed by a professional transcription service which is compliant with Australian government privacy standards. Any publications or conference papers will only contain results from responses that are de-identified.

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Storage of data

Access to the data during the study will be restricted to the chief investigator and research staff who have a log-on and a secure password to the data files. After the project is completed and the findings are published, the on-line data files will be archived and stored in Monash University password protected system for a period of 7 years. Any hard copies will be destroyed.

Access to the on-line data files after the project is archived will be restricted to the research team and with a relevant ethics approval. After 7 years, the archived data files will be destroyed. The storage and the destruction of all data will adhere to Monash University regulations.

Use of data for other purposes

Data from the study may be used in future projects if you consent to this, where ethics approval has been granted.

Results

Study findings will be made available through publications and conference presentations. A brief summary report will be provided on the Rehabilitation, Ageing and Independent Living Research Centre (RAIL) website of Monash University. A plain language summary (de-identified) will be provided on the RAIL website and forwarded to you at the end of the project.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

The executive Officer

Monash University Human Research Ethics Committee (MUHREC)

Room 111, Chancellery Building D,

26 Sports Walk, Clayton Campus

Research Office

Monash University VIC 3800

Tel: +61 3 9905 2052

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Thank you.

Professor Keith Hill (Chief Investigator)

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EXPLANATORY STATEMENT

People with mild dementia/cognitive impairment

Project ID: 39672

Project title: Changing the focus: Facilitating engagement in physical activity for people with dementia in a local community – Optional interviews

Chief investigator: Prof Keith Hill

Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: keith.hill@monash.edu

Project manager: Dr Angel Lee

Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: angel.lee@monash.edu

You are invited to take part in this study. Please read this Explanatory Statement before deciding whether or not to participate in this research. If you would like further information regarding any part of this project, you can contact the researchers via email addresses listed above.

Why are you invited for this research?

You are invited to participate in this study because you have been participating in the “Changing the Focus” physical activity program. The “Changing the Focus” program is a 12-month personalised physical activity program. It may consist of local community exercise programs, home-based exercises or a combination of these.

What does this research involve?

The aim of the interview is to find what may affect commencement and ongoing participation in the “Changing the Focus” physical activity program. This will involve participating in an in-person or online interview to gather your experience and opinions about the program (around 30 minutes and audio recorded), after the six-month assessment visit or at the time you stop participating in the program.

Source of funding

This research is funded by the National Centre for Healthy Ageing, Monash University.

Consenting to participate in the project and withdrawing from the research

Being part of this study is voluntary. Signing the consent form indicates you have given informed consent to take part in an optional interview, and agree to the use of your data for evaluating the program. You may withdraw from the interview at any time by notifying the study therapist or project manager as soon as possible. There will be no follow-up by the research team or the referrer (if this applies to you) if you withdraw. The information already collected from you will be used to evaluate the program and cannot be withdrawn.

Possible benefits and risks to participants

There will be no direct benefit to you from participating in the optional interviews. However, your participation will contribute to the future improvement of the “*Changing the focus*” program.

Services on offer if adversely affected

There is a slight chance that you may feel uncomfortable answering some questions in the optional interview. You can ask to pause the interview until you are ready or stop the interview at any time. If you require counselling, you can call the National Dementia Helpline on [1800 100 500](tel:1800100500). The researcher will be able to help with this process or you can visit your GP for more advice.



Payment

You will be paid a \$50 e-gift card to thank you for your time in the interview. This interview may be conducted together with or separate to your carer.

Confidentiality

Any information obtained in the interview that may identify you and/or your carer will be de-identified at the completion of the study. The interview audio recording will be transcribed by a professional transcription service which is ISO certified and fully compliant with Australian government privacy standards. Any publications or conference papers will only contain results from de-identified responses.

Storage of data

Access to the data during the study will be restricted to the chief investigator and research staff who have a log-on and a secure password to the data files. After the project is completed and the findings are published, the on-line data files will be archived and stored in Monash University password protected system for a period of 7 years. Any hard copies, interview audio and transcripts will be destroyed.

Access to the on-line data files after the project is archived will be restricted to the research team and with a relevant ethics approval. After 7 years, the archived data files will be destroyed. The storage and the destruction of all data will adhere to Monash University regulations.

Use of data for other purposes

Data from the study may be used in future projects if you consent to this, where ethics approval has been granted.

Results

Study findings will be made available through publications and conference presentations. A brief summary report will be provided on the Rehabilitation, Ageing and Independent Living Research Centre (RAIL) website of Monash University. A plain language summary (de-identified) will be provided on the RAIL website and forwarded to you at the end of the project.

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Thank you.

Professor Keith Hill (Chief Investigator)

EXPLANATORY STATEMENT**Carers of people with mild dementia/cognitive impairment****Project ID: 39672****Project title: Changing the focus: Facilitating engagement in physical activity for people with dementia in a local community - A feasibility study****Chief investigator name: Prof Keith Hill**Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: keith.hill@monash.edu**Project manager: Dr Angel Lee**Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
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You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any part of this project, you can contact the researchers via email addresses listed above.

What does the research involve?

The purposes of the study are to:

- Run the “Changing the Focus” physical activity program in Frankston/Mornington Peninsula (see below for a description of what the program involves)
- Evaluate the uptake of the “Changing the Focus” physical activity program
- Assess health and wellbeing outcomes for people with mild dementia/cognitive impairment
- Estimate support and health care costs for the person living with mild dementia/cognitive impairment and program running costs

Carers of people living with mild dementia or cognitive impairment who take part in the “Changing the Focus” program will be invited to take part.

The “Changing the Focus” program is a 12-month personalised physical activity program designed to meet the physical activity goal/s of the person with mild dementia or cognitive impairment. The program may consist of local community exercise programs, home-based exercises or a combination of these.

Before the program begins, a study therapist will:

- Visit you (and the person you provide care for) at home to complete the consent forms, collect information about yourself (and the person with dementia who you provide care for) and perform some tests to assess the person’s physical health and wellbeing. This may take about 2.5 hours with a rest break.
- Check that the person you provide care for is able to give consent to participate in the study. If they are unable to consent for themselves, you can provide consent on their behalf if you are their Enduring Power of Attorney or next of kin. You will be asked to sign a separate consent form for your involvement in the study.
- Discuss with you (and the person you provide care for) about physical activity options and set personalised goals.
- Teach you (and the person) how to fill in a falls and exercise diary.

During the 12-month program, you will:

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- Support the person who you care for to attend the chosen physical activity program(s) and/or supervise the person to do the home exercises as provided by the study therapist. This would start within 2 weeks from the first home visit.
- Complete the falls and exercise diary every week.
- Take part in 3 more home visits (at week 3, month 6 and 12). This may take about 1 hour each visit. The study therapist will discuss the involvement of the person you provide care for in the program and provide support for ongoing involvement.
- Take 7 calls from the study therapist to provide support for ongoing involvement in the program. The calls will be spread out in the first 6 months, and be about 20 minutes each call.
- Provide the data from your person's falls and exercise diary at each visit and support call to the study therapist.

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Additional home visits and phone calls can be arranged if you require extra support.

Why are you invited for this research?

You are invited to participate in this study because the person you care for has been referred by their health professional, case manager, family member or friend to the program or you have seen the advertisement and decide to take part.

Source of funding

This research is funded by the National Centre for Healthy Ageing, Monash University.

Consenting to participate in the project and withdrawing from the research

Being part of this study is voluntary. Signing the consent form indicates you have given informed consent to take part in the program and evaluations, and permit the use of your, or your person's data for evaluating the program.

You may withdraw from the study at any time by notifying the study therapist or project manager as soon as possible. However, if the person you care for depends on your support to participate in this program, it may mean that they will also have to withdraw from the program.

There will be no follow-up by the research team or the referrer (if this applies to the person you care for) if you withdraw. There will no implications of withdrawal. The information already collected from you in each home visit and phone call up to the time you withdraw from the study will be used to evaluate the program and cannot be withdrawn.

Possible benefits and risks to participants

You may see improved physical health and wellbeing in the person who you care for. There can be an increased risk of falls in people with mild dementia or cognitive impairment when exercising. Research shows that taking part in health professional prescribed exercise programs can be safe and feasible.

Falls risk will be minimised through supervision of exercises by the physical activity provider and/or you during the program. The research team will provide training and resources to ensure safety during exercise. People with mild dementia, carers and physical activity providers will be supported by the study therapist with regular contacts.

Services on offer if adversely affected

While we will make every effort to prevent a fall, it can happen. If the person you care for falls during the physical activity program, the exercise provider will check their injury and apply first aid if required. The exercise provider will follow their organisation's policy and notify you. If the injury is serious, the provider will call for an ambulance and stay with the person until help arrives. The exercise provider will report the

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incident to the research team. The research team will work together with the exercise provider, you, the person you provide care for (and their medical practitioner if applicable) to decide whether continuing in this study is appropriate.

If the person you provide care for has a fall or adverse event, it is recommended you seek medical help from their medical practitioner or call for an ambulance. Your person with dementia should not to continue with the home exercises until the chief investigator/project manager or study therapist reviews or modifies the program and decides whether it is appropriate to continue participation in this study.

If you require counselling, you can call the National Dementia Helpline on [1800 100 500](tel:1800100500). The researcher will be able to help with this process or you can visit your GP for more advice.

Payment

There is no payment for taking part in the physical activity program. Depending on the chosen physical activity program(s), the person who you care for (or you) may need to pay a low cost in order to attend the program(s) and meet the associated transportation cost for the 12-months' duration.

Confidentiality

Any information obtained in the study that may identify you and/or the person you provide care for will be de-identified at the completion of the study.

Any publications or conference papers will only contain results from de-identified responses.

Storage of data

Access to the data during the study will be restricted to the chief investigator and research staff who have a log-on and a secure password to the data files. After the project is completed and findings are published, the on-line data files will be archived and stored in Monash University password protected system for a period of 7 years. Any hard copies of the data will be destroyed.

Access to the on-line data files after the project is archived will be restricted to the research team and with a relevant ethics approval. After 7 years, the archived data files will be destroyed. The storage and the destruction of all data will adhere to Monash University regulations.

Use of data for other purposes

Data from the study may be used in future projects if you consent to this, where ethics approval has been granted.

Results

Study findings will be made available through publications and conference presentations for the scientific or clinical community. A brief summary report will be provided on the Rehabilitation, Ageing and Independent Living Research Centre (RAIL) website of Monash University. A plain language summary (de-identified) will be provided on the RAIL website and forwarded to you at the end of the project.

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

The executive Officer
Monash University Human Research Ethics Committee (MUHREC)
Room 111, Chancellery Building D,
26 Sports Walk, Clayton Campus

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Research Office
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Thank you.
Professor Keith Hill (Chief Investigator)

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EXPLANATORY STATEMENT

Carers of people with mild dementia/cognitive impairment

Project ID: 39672

Project title: Changing the focus: Facilitating engagement in physical activity for people with dementia in a local community – Optional interviews

Chief investigator: Prof Keith Hill

Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: keith.hill@monash.edu

Project manager: Dr Angel Lee

Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: angel.lee@monash.edu

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any part of this project, you can contact the researchers via email addresses listed above.

Why are you invited for this research?

You are invited to participate in this study because the person you care for has been participating in the “Changing the Focus” physical activity program for people with mild dementia. The “Changing the Focus” program is a 12-month personalised physical activity program. It may consist of local community exercise programs, home-based exercises or a combination of these.

What does the research involve?

The aim of this research is to find what may affect commencement and ongoing participation in the “Changing the Focus” physical activity program by the person you care for. We are interested in the perspectives of you as a carer of a person involved in the program, as well as the program participants. Your involvement will consist of participating in an in-person or online interview (around 30 minutes and audio recorded), after the six-month assessment visit for the person you care for, or at the time the person you care for decides to stop participating in the program.

Source of funding

This research is funded by the National Centre for Healthy Ageing, Monash University.

Consenting to participate in the project and withdrawing from the research

Being part of this study is voluntary. Signing the consent form indicates you have given informed consent to take part in an interview (optional), and permit the use of your data for evaluating the program.

You may withdraw from the interview at any time by notifying the study therapist or project manager as soon as possible.

There will be no follow-up by the research team or the referrer (if this applies to the person you care for) if you withdraw from the interview. There will no implications of withdrawal. Information already collected will be used to evaluate the program and cannot be withdrawn.

Possible benefits and risks to participants

There will be no direct benefit to you from participating in the optional interviews. However, your participation will contribute to the future improvement of the “*Changing the focus*” program. This has the



potential to improve health outcomes for older people with mild dementia or cognitive impairment in the future.

Services on offer if adversely affected

There is a slight chance that you may feel uncomfortable answering some questions in the optional interview. You can ask to pause the interview until you are ready or terminate the interview at any time during the interview.

If you require counselling, you can call the National Dementia Helpline on [1800 100 500](tel:1800100500). The researcher will be able to help with this process or you can visit your GP for more advice.

Payment

You will be paid a \$50 e-gift card to thank you for the interview. This interview may be conducted together with or separate to the person with dementia who you provide care for.

Confidentiality

Any information obtained in the interview that may identify you and/or the person you provide care for will be de-identified at the completion of the study. The interview audio recording will be transcribed by a professional transcription service which is ISO certified and fully compliant with Australian and international government privacy standards.

Any publications or conference papers will only contain results from de-identified responses.

Storage of data

Access to the data during the study will be restricted to the chief investigator and research staff who have a log-on and a secure password to the data files. After the project is completed and findings are published, the on-line data files will be archived and stored in Monash University password protected system for a period of 7 years. Any hard copies, interview audio and transcripts will be destroyed.

Access to the on-line data files after the project is archived will be restricted to the research team and with a relevant ethics approval. After 7 years, the archived data files will be destroyed. The storage and the destruction of all data will adhere to Monash University regulations.

Use of data for other purposes

Data from the study may be used in future projects if you consent to this, where ethics approval has been granted.

Results

Study findings will be made available through publications and conference presentations for the scientific or clinical community. A brief summary report will be provided on the Rehabilitation, Ageing and Independent Living Research Centre (RAIL) website of Monash University. A plain language summary (de-identified) will be provided on the RAIL website and forwarded to you at the end of the project.

Complaints

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Thank you.

Professor Keith Hill (Chief Investigator)



EXPLANATORY STATEMENT

Referrers

Project ID: 39672

Project title: Changing the focus: Facilitating engagement in physical activity for people with dementia in a local community - A feasibility study

CI name: Prof Keith Hill

Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: keith.hill@monash.edu

Project manager: Dr Angel Lee

Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: angel.lee@monash.edu

You are invited to take part in this study. Please read this Explanatory Statement in full before deciding whether or not to participate in this research. If you would like further information regarding any part of this project, you can contact the researchers via email addresses listed above.

What does the research involve?

The purposes of the study are to:

- Run the “Changing the Focus” physical activity program in Frankston/Mornington Peninsula (see below for a description of the program)
- Evaluate the uptake of the “Changing the Focus” program
- Find factors that may affect program uptake

The “Changing the Focus” is a 12-month personalised physical activity program designed to meet the physical activity goal of the person with mild dementia or cognitive impairment. The program may consist of supporting participation in local community exercise programs, home-based exercises (provided by the study therapist) or a combination of these, by people with mild dementia.

Participation in this study will involve taking part in an interview (conducted in person or online) to gather your experience and opinions about the Changing the Focus program (around 30 minutes, and audio recorded).

Why were you invited for this research?

You are invited to participate in this study because you are working in the Frankston/Mornington Peninsula region and have referred one or more people with dementia/cognitive impairment to the Changing the Focus physical activity program. The interview will be aimed to occur approximately one month after one or more referrals to the program by you.

Source of funding

This research is funded by the National centre for Healthy Ageing, Monash University.

Consenting to participate in the project and withdrawing from the research

Participation in this study is voluntary. Signing the consent form indicates you have given informed consent to take part in the interview, and permit the use of this data for evaluating the program.

You may withdraw from the study at any time by notifying the project manager as soon as possible. There will be no follow-up by the research team or your organisation from your withdrawal. There will no



implications of withdrawal. The information that was collected from you in the interview up to the time you withdraw from the study will be used to evaluate the program and cannot be withdrawn.

Possible benefits and risks to participants

There will be no direct benefit to you from participation in the optional interview. However, your participation will contribute to the future improvement of the “*Changing the focus*” program. This has the potential to improve health outcomes for older people with mild dementia or cognitive impairment.

Services on offer if adversely affected

There is a slight chance that you may feel uncomfortable answering some questions in the interview. You can ask to pause the interview until you are ready or terminate the interview at any time during the interview.

If you require counselling, you can call the National Dementia Helpline on [1800 100 500](tel:1800100500). The researcher will be able to help with this process or you can visit your GP for more advice.

Payment

If you take part in the interview, you will be paid a \$50 e-gift card to thank you for your time in the interview.

Confidentiality

Any information obtained in the study that may identify you and/or your carer will be de-identified at the completion of the study. The interview audio recording will be transcribed by a professional transcription service which is ISO certified and fully compliant with Australian government privacy standards.

Any publications or conference papers will only contain results from responses that are pooled together or individual response de-identified.

Storage of data

Access to the data during the study will be restricted to the chief investigator and research staff who have a log-on and a secure password to the data files. The on-line data files will be archived and stored in Monash University password protected system for a period of 7 years. After this time, the data will be destroyed. Any hard copies, interview audio and transcripts will be destroyed (after project completion and publication). The storage and the destruction of data will adhere to Monash University regulations.

Access to data after the project is completed will be restricted to the research team and with a relevant ethics approval.

Use of data for other purposes

Data from the study may be used in future projects if you consent to this, where ethics approval has been granted.

Results

This will be made available by publications and conference presentations for the scientific or clinical community. A brief summary report will be provided on the rehabilitation, Ageing and Independent Living Research Centre (RAIL) website of Monash University. A plain language summary (de-identified) will be provided on the RAIL website and forwarded to you if you request a copy.

Complaints



MONASH University

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Thank you.

Professor Keith Hill (Chief Investigator)

EXPLANATORY STATEMENT

Exercise providers

Project ID: 39672

Project title: Changing the focus: Facilitating engagement in physical activity for people with dementia in a local community - A feasibility study

CI name: Prof Keith Hill

Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: keith.hill@monash.edu

Project manager: Dr Angel Lee

Rehabilitation, Ageing and Independent Living Research
Centre, Monash University
email: angel.lee@monash.edu

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What does the research involve?

The purposes of the study are to:

- Run the “Changing the Focus” physical activity program in Frankston/Mornington Peninsula (see below for a description of the program)
- Evaluate the uptake of the “Changing the Focus” program
- Find factors that may affect program uptake

The “Changing the Focus” is a 12-month personalised physical activity program designed to meet the physical activity goal of the person with mild dementia or cognitive impairment. The program may consist of supporting participation in local community exercise programs, home-based exercises (provided by the study therapist) or a combination of these, by people with mild dementia.

Participation in this study will involve taking part in an interview (conducted in person or online) to gather your experience and opinions about the program (around 30 minutes, and audio recorded).

Why were you invited for this research?

You are invited to participate in this study because you are working in the Frankston/Mornington Peninsula region and have had one or more people with mild dementia from the Changing the Focus program participating in physical activity program/s you run. The interview will be aimed to occur approximately 6 months after one or more participants with mild dementia from the Changing the Focus program have been participating in your physical activity program/s.

Source of funding

This research is funded by the National centre for Healthy Ageing, Monash University.

Consenting to participate in the project and withdrawing from the research

Participation in this study is voluntary. Signing the consent form indicates you have given informed consent to take part in the interview, and permit the use of this data for evaluating the program.

You may withdraw from the study at any time by notifying the project manager as soon as possible. There will be no follow-up by the research team or your organisation from your withdrawal. There will no



implications of withdrawal. The information that was collected from you in the interview up to the time you withdraw from the study will be used to evaluate the program and cannot be withdrawn.

Possible benefits and risks to participants

There will be no direct benefit to you from participation in the optional interviews. However, your participation will contribute to the future improvement of the “*Changing the focus*” program. This has the potential to improve health outcomes for older people with mild dementia or cognitive impairment.

Services on offer if adversely affected

There is a slight chance that you may feel uncomfortable answering some questions in the interview. You can ask to pause the interview until you are ready or terminate the interview at any time during the interview.

If you require counselling, you can call the National Dementia Helpline on [1800 100 500](tel:1800100500). The researcher will be able to help with this process or you can visit your GP for more advice.

Payment

If you take part in the interview, you will be paid a \$50 e-gift card to thank you for your time in the interview.

Confidentiality

Any information obtained in the study that may identify you and/or your carer will be de-identified at the completion of the study. The interview audio recording will be transcribed by a professional transcription service which is ISO certified and fully compliant with Australian government privacy standards.

Any publications or conference papers will only contain results from responses that are pooled together or individual response de-identified.

Storage of data

Access to the data during the study will be restricted to the chief investigator and research staff who have a log-on and a secure password to the data files. The on-line data files will be archived and stored in Monash University password protected system for a period of 7 years. After this time, the data will be destroyed. Any hard copies, interview audio and transcripts will be destroyed (after project completion and publication). The storage and the destruction of data will adhere to Monash University regulations.

Access to data after the project is completed will be restricted to the research team and with a relevant ethics approval.

Use of data for other purposes

Data from the study may be used in future projects if you consent to this, where ethics approval has been granted.

Results

This will be made available by publications and conference presentations for the scientific or clinical community. A brief summary report will be provided on the rehabilitation, Ageing and Independent Living Research Centre (RAIL) website of Monash University. A plain language summary (de-identified) will be provided on the RAIL website and forwarded to you if you request a copy.



MONASH University

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

The executive Officer

Monash University Human Research Ethics Committee (MUHREC)

Room 111, Chancellery Building D,

26 Sports Walk, Clayton Campus

Research Office

Monash University VIC 3800

Tel: +61 3 9905 2052

Email: muhrec@monash.edu

Fax: +61 3 9905 3831

Thank you.

Professor Keith Hill (Chief Investigator)