CHINESE ISUPPORT PROGRAM IMPLEMENTATION GUIDE

How to implement the Chinese iSupport program in your organisation







Aged Care Research & Industry Innovation

Australia





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AND TEAM MEMBERS ON THE ARIIA GRANT

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Aged Care Research & Industry Innovation Australia









How can we embed a Chinese iSupport program in routine aged care services to optimise support for carers of people with dementia?

WHAT IS THE USUAL CHINESE ISUPPORT PROGRAM AND THE TAILORED CHINESE ISUPPORT PROGRAM?

The usual Chinese iSupport program:

The tailored Chinese iSupport program

The program aims to help carers access the iSupport for Dementia Manuals in simplified Chinese, traditional Chinese and associated resources such as iSupport audiobooks. The program is designed to enable carers to improve their capabilities in dementia care and reduce stresses. The program aims to provide tailored support for carers by assigning them to a trained iSupport facilitator, engaging them in dementia skill training using the Chinese iSupport for Dementia Manuals and resources, facilitating peer support and access to care services.

HOW DID WE IMPLEMENT IT?

The aged care organisations in the project nominated iSupport facilitators who were trained to work with frontline staff to deliver the usual Chinese iSupport program to carers. The iSupport facilitators were also trained and received ongoing support from their supervisors and the project team to deliver the tailored Chinese iSupport program to carers.

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WHAT DID WE FIND?

The tailored iSupport program demonstrated positive effects for carers on their mental-healthrelated quality of life, self-efficacy in responding to changed behaviours of people with dementia and controlling upsetting thoughts of caregiving, quality of care experiences, completion of the iSupport manual and satisfaction with the program, compared to those in the usual iSupport program.

The usual iSupport program demonstrated positive effects for carers on capabilities of obtaining respite care.

Facilitators could embed the training sessions for support workers in existing staff meetings. Support workers could deliver the usual iSupport program to carers in their routine contacts with their clients.

Aged care organisations in the project have initiated to sustain the usual iSupport program in their routine care services after the project life. However, they have identified the need to access funding sources for carers to sustain the tailored iSupport program.

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CHAPTER 1 OUTLINE OF THE EVIDENCE-BASED CHINESE ISUPPORT PROGRAM

What did we find from the Chinese iSupport program?

Why is iSupport for Dementia program important?

Over 55 million people live with dementia globally and approximately 25% of them live in Australia and China (Alzheimer's Disease International, 2018).

People with dementia show higher dependence on family carers compared to those without dementia (Alzheimer's Disease International, 2018). Moreover, around 95% of people with dementia from a Chinese background reside at home and are cared for by family members, compared to 55% in Europe Western (Alzheimer's Disease International, 2018).

Low utilisation of dementia and aged care services by Chinese carers is attributed to the influence of Confucianism that encourages people to make sacrifices to care for their aged parents and family members (Yiu et al., 2021). While family carers provide most care activities, they are less prepared with dementia care knowledge and skills than professional carers (WHO, 2019; World Health Organization, 2021).

The World Health Organization (WHO) has developed the iSupport for Dementia program, a comprehensive online or manual psychoeducation program for informal carers, to support the global dementia care action plan (WHO, 2019). Researchers in Australia and China have been working in a systemic and collaborative way to develop and evaluate the Chinese iSupport program and embed it to routine care services in the health care and social care systems as described in this chapter.

Translation and cultural adaptation of the iSupport

Our team across Australian and China has translated the iSupport from English into Chinese and culturally adapted it in the Chinese-Australian community and China based on the WHO adaptation guidelines (Xiao, Ye, et al., 2022). We have also engaged stakeholders in the translation and cultural adaptation process to ensure the acceptability of the program in the community. Chinese iSupport includes six modules: Introduction to dementia; Being a carer; Caring for me; Providing everyday care and Dealing with changed behaviours; and My engagement in consumer-directed care. The leaning modules and unites are listed in Table 1.

Modules	Units
1. Introduction to dementia	1. What is dementia?
2. Being a carer	 The journey together Improving communication Supported decision-making Involving others
3. Caring for yourself	 Reducing stress in everyday life Making time for pleasant activities Thinking differently
4. Providing everyday care	 Eating and drinking-more pleasant mealtimes Eating, drinking and preventing health problems Toileting and continence care Personal care An enjoyable day
5. Dealing with changed behaviour	 Introduction to behaviour changes Memory loss Aggression Depression, anxiety and apathy Difficulty sleeping Delusions and hallucinations Repetitive behaviour Walking and getting lost Changes in judgement Putting it all together
6. Consumer-directed aged care and dementia care	 Making informed choices in dementia care Services that are available for younger onset dementia Carer support Dementia Behaviour Management Advisory Service Home care packages Relinquishing the carer role

Table 1 iSupport leaning modules and units

The effectiveness of and carers' experiences in the iSupport program

Our team evaluated the effectiveness and cost-effectiveness of and carers' experiences in the Chinese iSupport program in a 9-month trial with 266 carer participants across multiple study sites in Australia and greater China (Xiao, Wang, et al., 2022; Xiao et al., 2024). Carers in the iSupport intervention group in the trial: 1) utilised iSupport to develop knowledge, skills and positive thoughts in the care of people with dementia; 2) received support from a trained iSupport facilitator to navigate and access care services and resources people with dementia and their carers needed; 3) participated in monthly online carer support group meetings facilitated by the iSupport facilitators to share their experience in the program; 4) connected with other carers via a social media platform to support each other and overcome social isolation. The results from the trial reveal that the iSupport program can improve carers' mental health-related quality of life and self-efficacy in controlling upsetting thoughts; and reduce distress. Moreover, the program can improve carers' meaningful interactions with peers and program facilitators which enhance their dementia care capabilities and sense of social support.

Carers' perceived needs when disseminating the iSupport program

The project team conducted a survey with carers across Australia (Yu et al., 2023) and China (Xu et al., 2024) to assess their needs in disseminating the iSupport program. Findings in Australia confirmed that most carers (88%) did not attend dementia education due to language barriers (59%); were too time-poor to attend (36%) with other reasons (15%). Most carers (80%) were not offered opportunities to participate in peer support groups in their preferred language. All carers would like to engage in Chinese iSupport manual as a self-learning tool; 88% of them would like to have a facilitator to support them in the Chinese iSupport program and 72% would like to allocate some of the home care package budget to pay for the facilitator-led tailored carer support. They suggested the use of the iSupport audiobook (81%) as they did not have time to read it. Fifty percent of carers recommended having a hardcopy of the iSupport book or an eBook (50%) for those without a computer to access to web-based iSupport.

- 88% of carers had not attended dementia education due to language barrier barriers (59%) and time constraints (36%).
- 80% were not offered peer support groups in their preferred language.
- All carers expressed a desire to use the Chinese iSupport manual as a self-learning tool.
- 88% wanted a facilitator to support them in the Chinese iSupport program.
- 72% were willing to allocate part of their home care package budget for the facilitator-led tailored support.
- 81% suggested using an audiobook format due to lack of time for reading.
- 50% recommended a hardcopy or eBook version for those without computer access.

CHAPTER 2

EMBEDDING THE CHINESE ISUPPORT PROGRAM TO YOUR ORGANISATION'S CARE SERVICES

How do health care and aged care organisations embed the iSupport program to routine care services?

We have developed these iSupport resources as listed in Table 2. There are multiple ways for your organisation to embed the Chinese iSupport program and/or resources to routine care services depending on the care needs of people with dementia and their carers as we discussed in the following sections.

Categories 类别	Content 内容	Where to access and download? 访问或下载方法
Chinese iSupport information sheet 中文 iSupport 传单	Brief instruction to access the Chinese iSupport program and resources; using QR code to access all resources 访问中文 iSupport 计划和资源的 简要说明;使用二维码访问所有资 源	See Appendices 1 and 2
Web-based Chinese iSupport program 网站版 iSupport课程 (NFACR)	Six modules and 29 units 完整的iSupport模块和单元	Simplified Chinese: 简体中文版 <u>http://43.135.6.171:8080/suppor</u> <u>t_cns/</u> Traditional Chines: 繁体中文版 <u>http://43.135.6.171:8080/suppor</u> <u>t_cnt/</u>
Chinese iSupport e-books电子书 (NFACR)	Six modules and 29 units 完整的iSupport模块和单元	<u>Simplified Chinese: 简体中文版</u> <u>Traditional Chines: 繁体中文版:</u>
Chinese iSupport audiobooks有 声书 (ARIIA and NFACR)	完整的iSupport模块和单元	 <u>Mandarin: 普通话版</u> <u>Cantonese: 澳大利亞失智症照</u> <u>顧者培訓和支援手冊: 粵語版</u>

Table 2 Chinese iSupport resources

Using the Chinese iSupport information sheet to disseminate iSupport resources

We have developed a "Simplified Chinese iSupport information sheet" and a "Traditional Chinese iSupport information sheet" to introduce the iSupport resources we listed in Table 2. If your organisation intent to use these resources, you will need to appoint an iSupport facilitator to dissemination the resource. The iSupport facilitator can use staff development sessions, staff meetings or other opportunities to introduce the Chinese iSupport information sheet to support workers who deliver direct care to people with dementia. The iSupport facilitator will need to work with support workers to disseminate iSupport resources to carers of people with dementia.

Opportunities to disseminate iSupport resources include, but are not limited to distributing the Chinese iSupport information sheet to:

- Dementia carer support groups,
- People with dementia and their carers involved in health education and health promotion activities,
- People with dementia and their carers in hospital discharge plan,
- You can also use newsletter, social media platforms and email etc. to distribute the Chinese iSupport information sheet to relevant audience.

Health professionals and support workers who deliver direct care services to people with dementia are in an ideal position to introduce the iSupport resources to carers in various settings, for example memory clinics, geriatric clinics, geriatric wards, dementia care units, respite care centres, home care package. They can distribute the Chinese iSupport information sheet to carers of people with dementia in these care settings.

Implementing "the usual Chinese iSupport program"

Based on our experiences, some carers are capable of using the Chinese iSupport information sheet to access and utilise iSupport resources without additional help from professional staff. However, some carers do need help from staff to access and utilise the iSupport resources due to low digital literacy level. Therefore, the iSupport facilitator will need to train staff to help carers access and utilise the iSupport manuals and resources. The module three in this book provides a step-by-step instruction for accessing and utilising the iSupport resources. The iSupport facilitator can use the module three to train staff.

Training support for aged care organisations to implement "The tailored Chinese iSupport program"

Flinders University iSupport team offers training and consultation services for aged care organisations to implement "The tailored Chinese iSupport program". Please contact the project leader, Professor Lily Xiao (lily.xiao@flinders.edu.au) to discuss your needs and requests.

CHAPTER 3 INSTRUCTIONS FOR CARERS OF PEOPLE WITH DEMENTIA TO ACCESS AND UTILISE THE CHINESE ISUPPORT PROGRAM

How do carers access and utilise the iSupport program?

1. Accessing the Website



Simplified Chinese: http://43.135.6.171:8080/support_cns/ (Australian link) Traditional Chinese: http://43.135.6.171:8080/support_cns/ (Australian link) You will be prompted to sign up and register. Please follow the instructions in Step 2 to register.

2. How to register

2.1. Click on 'Register' on the homepage



在线支持

主页
Home page
关于我们
About us
项目海报
Project poster
线上研讨会记录
Recorded webinare
使用書指南
1100 Jm
1K9
密码
登录
80289

澳大利亚失智症照顾者在线支持

失智症照顾者在线支持项目(iSupport for Dementia)是由世界卫生组织协同全球失智症照顾 领域的专家团队共同完成的照顾者在线学习课程。在 演大利亚政府演中基金会资助下,我们开展了"通过 iSupport项目加强澳大利亚和大中华地区在失智症照 护领域的研究合作"的研究课题,通过研究将世界卫 生组织iSupport项目翻译成中文并进行了文化调适, 以供演大利亚讲华语的失智症照顾者使用。我们的研 究目的是:



请点击图片观看失智症照顾者在线支持简介

- 1. 通过失智症照顾者在线支持,加强澳大利亚与大中华地区在失智症照顾的研究合作。
- 2. 增进对使用华语的失智症照顾者经验的了解。
- 3. 展示演大利亚在失智症照顾政策、标准和服务方面的卓越表现。
- 4. 以中文失智症照顾者在线支持为契机,使凑大利亚的多元文化社区参与开发多语言项目。
- 5. 通过建立在线教育和在线失智症照顾者支持来应对COVID-19疫情所带来的挑战。

我们根据照顾者的需要,制作了以下三种iSupport版本: 1) iSupport在线学习网 站; 2) iSupport电子书; 3) iSupport有声书。请阅读"使用者指南"栏目,以了解如何使 用这些版本。我们在项目中开展了线上研讨会,请点击"线上研讨会记录"栏目, 获取研讨 会录像记录。

该项目的协作单位:

澳大利亚:福林达斯大学,新南威尔士大学,国立老年研究所,卧龙岗大学 大中华地区:北京大学精神卫生研究所,西安交通大学护理学院,臺北醫學大學護理學 院,香港中文大學醫學院,澳門鏡湖護理學院

2.2. Fill in your personal information.

在线支持	注册
主页	照顾者信息
Home page	12 A
关于我们	
About us	手机号或住宅电话号码
项目海报	
Project poster	宮 母 // / / / / / / / / / / / / / / / / / /
使用者指向	
11 1 1	→公知人室19 か後至少为4位字符
账号	性别
客码	● 第 O 女
88	作款
	性别 ○ 労 ◆ 文 年設 关系
	Ý
	请告诉我们如何称呼被照顾者?

2.3. The website will automatically review your registration information, which is expected to take around 10 minutes.

2.4. Log in to your personal account Enter your username and password to log in to your personal account.

	宿在照顾者在线支持 se iSupport for Dementia
在线支持	澳大利亚失智症照顾者在线支持
主页	失智症照顾者在线支持项目(iSupport for
Home page	Dementia)是由世界卫生组织协同全球失智症照顾
关于我们	领域的专家团队共同完成的照顾者在线学习课程。在 澳大利亚政府演中基金会资助下,我们开展了"通过
About us	iSupport项目加强演大利亚和大中华地区在失智症照
项目海报	护领域的研究合作"的研究课题,通过研究将世界卫 生组织Support 项目翻译成中文并进行了文化编造。
Project poster	以供澳大利亚讲华语的失智症照顾者使用。我们的研
线上研讨会记录	究目的是: 遺伝出图片观看失智症网族者在线支持,加强演大利亚与大中华地区在失智症网族的研究合作。
Recorded webinars	 増进对使用华语的失暂使期間者经验的了解。 展示導大利亚在失暂使時間政策、标准和服务方面的卓越表现。
使用者指南	3. 展示與大利亚住大會征照顾政策、标准和服务方面的单趋表现。 4. 以中文失智症照顾者在线支持为契机,使澳大利亚的多元文化社区参与开发多语言项目。
注册	5. 通过建立在线教育和在线失智症照顾者支持来应对COVID-19疫情所带来的挑战。 我们根据照顾者的需要,制作了以下三种iSupport版本: 1) iSupport在线学习网
1	站; 2) iSupport电子书; 3) iSupport有声书。请阅读 "使用者指南"栏目,以了解如何使
1	用这些版本。我们在项目中开展了线上研讨会,请点击"线上研讨会记录"栏目,获取研讨 会灵像记录。
80299 E	该项目的协作单位: 澳大利亚: 福林达斯大学,新南威尔士大学,国立老年研究所,卧龙岗大学 大中华地区: 北京大学精神卫生研究所,西安交通大学护理学院,臺北醫學大學護理學 院,香港中文大學醫學院,澳門鏡湖護理學院

2.5. The Chinese iSupport learning program consists of a total of 6 learning modules. Each module contains different learning units. By clicking on each learning unit, you will be able to embark on your learning journey.



- For specific instructions, please click the "Registration Video" link: Guide to Using the Dementia Caregiver Online Support Website.
- Simplified Chinese (Australia Website) : http://43.135.6.171:8080/support_cns/static/guideVideo.mp4
- Traditional Chinese (Australia Website) : <u>http://43.135.6.171:8080/support_cnt/static/guideVideo1.mp4</u>

3. Download various iSupport resources

Step 1: Click on the User Guide located at the bottom left corner of the homepage.



Step 2: Click on next page

使用者指南

在世界范围内,失智症人士的照护者应有权获得和使用根据他们的需要而描写的教育和培训课程,以使他们能有效地照护失智症人士,满足其身体、精神和社会的需要。

iSupport是基于循证的教育培训课程,是为满足照护者的需要而撰写的。它旨在提高照护者的知识和护理技能,例如照护者照护失智症人士的技能和自我照护 的技能。iSupport致力于支持照护者,以使失智症人士尽可能久地居家生活,同时预防和减轻照护者的压力。本课程包含的内容经过精心设计,以帮助照护者解决 他们在照顾有失智症的人时可能面临的挑战。

iSupport包含哪些内容?

表1列出了iSupport 课程概要。该课程分为五个学习模块,演大利亚中文版包括了六个学习模块

1.失智症简介 2.做一名照护者 3.照顾我 4.提供日常护理 5.应对行为改变 6.使用者导向的护理服务(演大利亚中文版)

Step 3: Click on next page

学习模块	学习单元
1失智症简介 介绍了什么是失智症,包括失智症人士会发生什么,如果您怀疑您的家人或朋友患有失智症您该怎么做。	1a 失智症简介(有声书)
2 做一名照顾者 专注于改善沟通,共同决策,并让其他人参与到失智症人士的照顾中来。	2a 相伴之旅(有声书) 2b 促进沟通(有声书) 2c 共同决策(有声书) 2d 寻求他人帮助(有声书)
3 照顾我 旨在通过赋予愉快的活动时间和改变思考模式来减少照护者的压力。	3a 舒缓日常生活的压力(有声书) 3b 为愉悦身心的活动寻找时间(有声书) 3c 不同的思维方式(有声书)
4 提供日常护理 专注于饮食,包括创造更多愉快的进餐时间,以及预防与失智症相关的健康问题,使用厕所、失菜照顾和 个人护理。	4a 饮食: 更加愉快的用餐时间(有声书) 4b 预防健康问题(有声书) 4c 如厕和失禁的护理(有声书) 4d 个人护理(有声书) 4e 愉快的生活(有声书)
5 应对行为改变 介绍了失智症人士可能发生的行为变化以及对照於者的影响。这些行为变化包括记忆丧失、攻击行为、抑 郁和焦虑、睡眠障碍、妄想和幻觉、重复行为、游走和走失、以及判断力下降或缺乏。	5a 行为改变简介(有声书) 5b 记忆丧失(有声书) 5c 攻击行为(有声书) 5d 抑郁和集感(有声书) 5e 護眠障碍(有声书) 5f 妄想和幻觉(有声书) 5g 重复行为(有声书) 5h 游走和走失(有声书) 5i 判断力下锋或缺乏(有声书) 5j 总结回顾(有声书)
6.使用者导向的护理服务(仅限于演大利亚中文版) 介绍了如何申请和使用联邦政府提供的各种老年护理服务,内容包括:对失智症护理服务作出明智的选择,年轻型失智症可选择的服务,照护者支持,失智症行为管理咨询服务,家居配套服务,帮助照护者退出照护者角色的活动和服务。	6a 对失智症护理服务作出明智的选择(有声书) 6b 年轻型失智症可选择的服务(有声书) 6c 照护者支持(有声书) 6d 失智症行为管理咨询服务(有声书) 6e 家居配套服务(有声书) 6f 帮助照护者退出照护者角色的活动和服务 (有声书)
共计: 6个学习模块	29个学习单元
+ <u></u> <u></u> <u></u> <u></u> <u></u> <u></u> + <u></u> <u></u> <u></u>	

Step 4: select audiobook or iSupport e-Book

步骤	如何操作	
1. 遙接到网页	点击: http://43.135.6.171:8080/support_cns/打开网页后,您将被要求报名注册。请按照步骤2的指示进行注册。	
2.如何注册	报名注册:在报名页面填写您的个人信息。	
3.审核注册	我们将审核您的注册信息,这一过程需要至少24小时。请您在注册24小时后登录并使用"失智症照顾者在线支持"。	
4.登录个人账号	输入您的用户名和密码,登录个人账号。	
5.开始模块学习	iSupport学习项目一共有六个学习模块。每个模块有不同的学习单元 (类似于课本里的一个个章节小课)。通过点击每个学习单元,您将能够开始您的学习之旅。	
具体操作请点击 "注册视频"链 接	"注册视频"链接	
 2.ISupport电子书: 请点击以下链接下载电子书,保存到您的电脑、IPad或手机阅读。您也可以根据您的需要,打印出有关的学习模块或学习单元进行阅读。 2.1.澳大利亚失智症照顧者培训和支持手册: 简体中文版 小 3.ISupport有声书: 请点击以下链接下载有声书,保存到您的电脑、IPad或手机听阅。 		
 3.1.澳大利亚失智症照顾者培训和支持有声书: 普通话版: 请参见表1中有声书下载链接。 3.2.澳大利亞失智症照顧者培訓和支援有声书: 粵語版: 請參見表1中有聲書下載鏈接(正在製作中)。 		
iSupport是照护者的自学工具。每个学习模块包含多个学习单元。所有学习单元的结构都是一致的。首先,每个学习单元会概述该单元的重要性,如何帮助您 成为好的照护者以及您将会学习到的内容。然后,课程会展示学习内容,比如简要阅读,个案分析,多项选择题以及练习活动来检验您学到的内容。您可选择学 习整个课程,也可挑选其中与您的情况相关的学习模块或学习单元来学。当然您也可以随时返回到各个模块再次学习。		

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APPENDICES

Appendix 1. Simplified Chinese iSupport information sheet 澳大利亚简体版iSupport信息手册



APPENDICES

Appendix 2. Appendix Traditional Chinese iSupport information sheet 澳大利亚繁体版iSupport信息手册



失智症	照顧者課程包括6個	書模組,29個學習課程
	學習模糊	1一 失智症简介
	第一節	失智症簡介
	學習模組	二 做一名照顾者
	第一節	相伴之族
	第二節	促進溝通
	第三節	共同决策
	第四節	尋求他人的支援

課程簡介	(續	
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	學習模組三 照顧我		
第一節	舒緩日常生活的壓力		
第二節	為愉悦身心的活動尋找時間		
第三節	不同的思維方式		
學習模組四 提供日常護理			
第一節	飲食:更加愉快的用餐時間		
第二節	飲食:預防健康問題		
第三節	如廁和失禁的讓理		
第四節	借人護理		
第五節	愉快的生活		
4	學習模組五 應對行為改變		
第一節	行為改變簡介		
第二郎	i 記憶喪失		
第三級	攻撃行為		
第四節	抑鬱和焦虑		
第五節	睡眠障礙		
第六節	妄想和幻覺		
第七節	重複行為		
第八節	遊走和走失		
第九節	判斷力下降或缺乏		
第十節	總結回顧		
學習相	貝組六 使用者導向的護理服務		
第一節	對失智症護理服務作出明智的選擇		
第二郎	有年輕型失智症的人可選擇的服務		
第三的	照顧者支援		
第四節	失智症行為管理諮詢服務		
第五節	家居配套服務		
第六節	幫助照顧者退出照顧者角色的活動和服務		





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