

2020 NATIONAL CARER SURVEY

Thank you for taking the time to complete this survey. By sharing your opinions and experiences, you will help the National Network of Carer Associations advocate for greater recognition and support of carers across Australia. Please take the time to read the enclosed Participant Information and Consent Form prior to participating.

There are two ways you can complete the survey:

- 1) Online via the website http://bit.ly/2020NationalCarerSurvey by 30 June 2020
- 2) By completing this form and returning it in the reply paid envelope provided, no later than 30 June 2020

The survey should take you approximately 20 minutes depending on your responses. You can leave any question blank if it does not apply to you, or if you would prefer not to answer. Your responses will be anonymous.

At the end of the survey, you will be asked whether you would like to be contacted for a follow-up study on the long-term effects of caring in 2022. You can participate in this survey regardless whether you choose to be part of the follow-up study.

By completing and returning this survey you indicate that you have read the enclosed Participant Information and Consent Form, that you voluntarily agree to participate, and that you are at least 16 years of age.

If you have any questions about this survey, please contact the Carers NSW Research Team on (02) 9280 4744 or email research@carersnsw.org.au.

SCREENING QUESTIONS

	RELITITO QUESTIONS	
1.	In which state or territory do you liv	e?
	Australian Capital Territory	New South Wales
	■ Northern Territory	Queensland
	South Australia	Tasmania
	☐ Victoria	Western Australia
2.	-	look after someone) who has a disability, mental illness, drug or on, dementia, terminal or serious illness, or who needs care due to
	Yes (go to Question 3)	
	☐ Not currently, but I have in the past	(go to Question 3)
	☐ No (unfortunately you do not fit ou	r respondent profile. Thank you for your interest.)
3.	Is/was the person you care(d) for a f	amily member, friend or neighbour?
	Yes (If you currently provide care go to Question 18)	please go to Question 4, if you no longer provide care please
	No, I care for the person(s) as paid we respondent profile. Thank you for you	vork (i.e., nurse, support worker) (Unfortunately you do not fit our our interest.)
	No, I care for the person(s) as a form Thank you for your interest.)	nal volunteer (Unfortunately you do not fit our respondent profile.

SECTION 1: THE CARING RELATIONSHIP

How many people do you care for? _____

ERS	SON 1	PER	SON 2
•	What is this person's gender?	5.	What is this person's gender?
	☐ Female		☐ Female
	Male		■ Male
	Non-binary / gender diverse		Non-binary / gender diverse
	Their gender identity isn't listed.They identify as:		Their gender identity isn't listed.They identify as:
	Prefer not to say		Prefer not to say
•	How old is this person?	6.	How old is this person?
	years		years
	What is this person's relationship to you?	7.	What is this person's relationship to you?
	They are my:		They are my:
	Parent or parent in law		Parent or parent in law
	Partner or spouse		Partner or spouse
	Child (incl. adult son or daughter)		Child (incl. adult son or daughter)
	☐ Brother or sister		Brother or sister
	Grandparent		Grandparent
	Friend		Friend
	Neighbour		Neighbour
	Other, please specify:		Other, please specify:
•	What is this person's cultural background? (e.g. Italian, Chinese, Australian, etc.)	8.	What is this person's cultural background? (e.g. Italian, Chinese, Australian, etc.)
•	Does this person speak a language other than English at home? (e.g. Vietnamese, Auslan)	9.	Does this person speak a language other than English at home? (e.g. Vietnamese, Auslan)
	Yes, they speak		☐ Yes, they speak
	■ No, English only		■ No, English only

PERSON 1 (continued) PERSON 2 (continued) Is this person of Aboriginal or Torres Strait Is this person of Aboriginal or Torres Strait Islander origin? Islander origin? □ No ☐ No Yes, Aboriginal Yes, Aboriginal Yes, Torres Strait Islander Yes, Torres Strait Islander Yes, both Yes, both Prefer not to say Prefer not to say For what conditions / disabilities / illnesses 11. For what conditions / disabilities / illnesses does this person need your care? does this person need your care? Please tick all that apply, even if the person you Please tick all that apply, even if the person you care for has not received an official diagnosis. care for has not received an official diagnosis. Physical disability Physical disability Sensory impairment (e.g. loss of hearing or Sensory impairment (e.g. loss of hearing or loss of vision) loss of vision) Frailty due to ageing Frailty due to ageing Intellectual disability Intellectual disability Autism Spectrum Disorder Autism Spectrum Disorder Mental illness Mental illness Drug or alcohol dependency Drug or alcohol dependency Dementia Dementia Chronic health condition Chronic health condition ☐ Terminal or serious illness ☐ Terminal or serious illness Acquired brain injury, stroke Acquired brain injury, stroke Neurological condition (e.g. epilepsy, Neurological condition (e.g. epilepsy, Parkinson's disease, multiple sclerosis) Parkinson's disease, multiple sclerosis) Other, please specify: Other, please specify: 12. Do you and the person you care for live in 12. Do you and the person you care for live in the same household? the same household? ☐ Yes ☐ Yes ■ No, they live separately ■ No, they live separately No, they live with another family member or No, they live with another family member or friend

No, they live in a care facility (e.g., nursing

■ No, they live in supported accommodation /

a group home

Other, please specify:

a group home

Other, please specify:

No, they live in a care facility (e.g., nursing

■ No, they live in supported accommodation /

PERSON 1 (continued) PERSON 2 (continued) Do any other family members / friends help Do any other family members / friends help 13. take care of this person? take care of this person? ☐ I am the only one who provides care ☐ I am the only one who provides care ☐ I provide the most care, but others help with ☐ I provide the most care, but others help with care sometimes care sometimes ☐ Someone else provides the most care, but I ☐ Someone else provides the most care, but I help with care sometimes help with care sometimes 14. How long can this person be left alone? 14. How long can this person be left alone? ☐ Not at all ☐ Not at all Less than an hour Less than an hour A few hours A few hours One day One day A few days A few days ☐ More than a few days ☐ More than a few days On average, how many hours per week do you On average, how many hours per week do you 15. 15. spend caring for this person? spend caring for this person? __ hours per week hours per week How long have you been caring for this How long have you been caring for this 16. 16. person? person? Less than 1 year Less than 1 year years ______ years 17. Have you previously cared for anyone who you are no longer caring for? □ No (Please go to Question 22) Please indicate who you have previously cared for, but are no longer caring for. If you cared for more 18. than one person in the past, please think of the person you cared for most recently: Parent or parent in law Partner or spouse Child (incl. adult son or daughter) Brother or sister Grandparent Friend Neighbour Other, please specify: _____ 19. How long did you care for this person?

4

20.

Less than 1 year
years

Less than a year ago
years ago

How long ago did this caring role end?

	Why did this caring role end?									
	Please tick all that apply.									
	The person I cared for no longer required care									
	 The person I cared for passed away Someone else took over the caring role, please tell us who (e.g. their child, sibling, or frien 	(d)								
	☐ I couldn't continue caring									
	Other, please specify:									
yοι	u are a former carer, and you are not currently providing care for someone, please go to Questic	on 40.								
SE	CTION 2: YOUR CARING ROLE									
2.	Please tick all the types of support you provide to the person(s) you care for. Please also tasks that require the most effort from you (5 = most effort, 1 = less effort). Please tick all that apply.	rank th	e 5							
		Tick	Rank							
	Personal care (e.g. eating, showering, dressing)									
	Mobility (e.g. walking, getting out of bed)									
	Communication (e.g. reading, writing, helping them articulate themselves in conversations)									
	Interpreting or translating for them from or into another language									
	Advocacy (e.g. helping them dispute a treatment or a decision)									
	Advocacy (e.g. helping them dispute a treatment or a decision) Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings)									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings)									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings) Help with organising finances (e.g. helping them budgeting, assisting with online banking)									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings) Help with organising finances (e.g. helping them budgeting, assisting with online banking) Handling their finances (e.g. making financial decisions for them, managing their accounts) Administrative support (e.g. filling out forms, sending emails or making phone calls on their									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings) Help with organising finances (e.g. helping them budgeting, assisting with online banking) Handling their finances (e.g. making financial decisions for them, managing their accounts) Administrative support (e.g. filling out forms, sending emails or making phone calls on their behalf) Coordinating support services or care workers (e.g. finding and booking services, dealing									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings) Help with organising finances (e.g. helping them budgeting, assisting with online banking) Handling their finances (e.g. making financial decisions for them, managing their accounts) Administrative support (e.g. filling out forms, sending emails or making phone calls on their behalf) Coordinating support services or care workers (e.g. finding and booking services, dealing with service providers)									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings) Help with organising finances (e.g. helping them budgeting, assisting with online banking) Handling their finances (e.g. making financial decisions for them, managing their accounts) Administrative support (e.g. filling out forms, sending emails or making phone calls on their behalf) Coordinating support services or care workers (e.g. finding and booking services, dealing with service providers) Health care (e.g. assisting with taking medication, injections, or wound care)									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings) Help with organising finances (e.g. helping them budgeting, assisting with online banking) Handling their finances (e.g. making financial decisions for them, managing their accounts) Administrative support (e.g. filling out forms, sending emails or making phone calls on their behalf) Coordinating support services or care workers (e.g. finding and booking services, dealing with service providers) Health care (e.g. assisting with taking medication, injections, or wound care) Transport (e.g. driving them to appointments, taking public transport with them)									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings) Help with organising finances (e.g. helping them budgeting, assisting with online banking) Handling their finances (e.g. making financial decisions for them, managing their accounts) Administrative support (e.g. filling out forms, sending emails or making phone calls on their behalf) Coordinating support services or care workers (e.g. finding and booking services, dealing with service providers) Health care (e.g. assisting with taking medication, injections, or wound care) Transport (e.g. driving them to appointments, taking public transport with them) Household chores (e.g. cleaning, cooking, shopping)									
	Cognitive or emotional tasks (e.g. making decisions, managing difficult feelings) Help with organising finances (e.g. helping them budgeting, assisting with online banking) Handling their finances (e.g. making financial decisions for them, managing their accounts) Administrative support (e.g. filling out forms, sending emails or making phone calls on their behalf) Coordinating support services or care workers (e.g. finding and booking services, dealing with service providers) Health care (e.g. assisting with taking medication, injections, or wound care) Transport (e.g. driving them to appointments, taking public transport with them) Household chores (e.g. cleaning, cooking, shopping) Property maintenance (e.g. mowing lawns, cleaning gutters)									

23. Do you feel confident that you have the necessary skills for what you are doing in your c							
	☐ Very confident ☐ Confident ☐ Somewhat confident ☐ Not at all confident ☐ Prefer not to say						
24.	Please tell us how your caring role has affected your relationships with the person you care for, your family or friends?						

SECTION 3: SERVICES AND SUPPORT

25. Does someone you care for currently use aged care services?

Please tick all that apply

Aged care services are services designed for people over the age of 65 years (or over the age of 50 years for
Aboriginal and Torres Strait Islander Australians). They may be government funded or purchased privately.

No, nobody that I care for currently needs aged care services (Please go to Question 28)
Yes, someone I care for uses entry-level, aged care services subsidised by the Commonwealth Home
Support Program (CHSP), such as cleaning, community transport, or basic in-home support
Yes, someone I care for has a Home Care Package (Level 1, 2, 3 or 4), a government funded package of support that enables them to purchase aged care services, such as personal care, or respite
Yes, someone I care for pays for aged care services privately, such as cleaning, or in-home support
Yes, someone I care for lives in residential aged care, for example a nursing home or care facility
Someone I care for is receiving aged care services, but I don't know which services they are using
Other, please specify: (Please go to Question 27)
Someone I care for needs aged care services but is currently unable to access these services
(Please go to Question 27)

26. Please indicate how much you agree with the following statements:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
When the person I care for a	accesses age	d care servi	ces			
I am asked about my needs as a carer						
I am provided with all the information I need						
The aged care services rece	ived by the p	erson I care	for			
give me a break from providing care						
enable me to keep my job, or go back to work						
meet the needs of the person I care for						
meet my needs as a carer (e.g. are available when I can't provide care)						
meet my expectations for quality and safety						
are easy to organise						

Have you or the person(s) you care for experienced any of the following challenges with aged care services? Please tick all that apply.									
☐ The person I care for was	s not eligible fo	r the require	d services						
☐ The service received was	s at a lower leve	l than what	was required						
☐ There was a long waiting	period to get a	assessed							
☐ There was a long waiting	period to acce	ess services							
☐ The services required we	ere not available	locally							
There were no culturally language spoken, or ger		vices availak	ole (e.g. accom	modating for	cultural backgr	ound,			
☐ There were concerns abo	-	or safety of t	he services						
☐ The cost of services (incl	uding co-payme	ents) was too	high						
☐ It was difficult to find info	ormation about	what service	es were availabl	e and how to	access them				
☐ It took too much time an	nd energy to org	ganise the se	ervices						
☐ The person(s) I care for c	lid not want to	use services							
Other, please describe:_									
☐ None of the above									
Does someone you care for currently receive support through the National Disability Insurance Scheme (NDIS)? Please tick all that apply. The National Disability Insurance Scheme (NDIS) provides government funded services to people under the age of 65 years who have a significant or permanent disability.									
■ No, nobody I care for currently needs disability services (Please go to Question 31)									
Yes, someone I care for has a National Disability Insurance Scheme plan (NDIS plan)									
Someone I care for needs the NDIS, but has not been able to access these services to date (Please go to Question 30)									
 Someone I care for uses disability services outside of the NDIS (Please go to Question 30) 									
Other, please specify:				(Please go t	o Question 30))			
☐ I don't know (Please go	to Question 30))							
How much do you agree with the following statements?									
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A			
The local area coordinator	· (LAC) / NDIS ¡	olanner							
asked about my needs as a carer									
provided me with all the information I needed									

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
The supports included in the	NDIS plan (1	for the pers	on I care for)	•		
give me a break from providing care						
enable me to keep my job, or go back to work						
meet the needs of the person I care for						
meet my needs as a carer (e.g. are available when I can't provide care)						
meet my expectations for quality and safety						
are easy to organise						
 □ The person I care for did not receive enough funding in their NDIS plan □ Services outside the NDIS (either in addition to, or instead of the NDIS) were not available □ There was a long waiting period to get assessed 						
There was a long waiting pThe services required wereThere were no culturally ap language spoken, or gender	not available opropriate ser er identity)	locally vices availab	-	modating for (cultural backgr	ound,
 The cost of services (included) It was difficult to find inform It took too much time and The person(s) I care for did Other, please describe: 	mation about energy to org not want to u	what service anise the se use services	s were availabl rvices	e and how to	access them	
■ None of the above Please leave any comments you	ou might have	on your exp	erience with di	sability servic	es:	

31. Does someone you care for currently use mental health services?

Please tick all that apply

Mental health services include government funded community services, hospital services and Medicare subsidised clinical support (e.g. psychology appointments) that assist people experiencing mental ill health or living with a mental illness.

No, nobody I care for currently needs mental health services (Please go to Question 34)
Yes, someone I care for uses hospital based mental health services as admitted patient or in out-of-hospital
care
Yes, someone I care for sees a private psychologist or psychiatrist
Yes, someone I care for uses community mental health services, such as drop-in clinics, or rehabilitation
programs
Someone I care for needs mental health services but has not been able to access these services to date
(Please go to Question 33)
I don't know (Please go to Question 33)
Other, please specify: (Please go to Question 33)

32. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
When the person I care for a	accesses men	tal health se	ervices			
I am asked about my needs as a carer						
I am provided with all the information I need						
The mental health services r	eceived by th	ne person l	care for			
give me a break from providing care						
enable me to keep my job, or go back to work						
meet the needs of the person I care for						
meet my needs as a carer (e.g. are available when I can't provide care)						
meet my expectations for quality and safety						
are easy to organise						

33.	Have you or the person(s) you care for experienced any of the following challenges with mental health services? Please tick all that apply.						
	The person I care for was not eligible for the required services						
	The service received was at a lower level than required The service received was at a lower level than required						
	☐ There was a long waiting period to access services						
	☐ The services required were not available locally						
	 There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity) 						
	☐ The cost of services (including co-payments) was too high						
	☐ It was difficult to find information about what services were available and how to access them						
	☐ It took too much time and energy to organise the services						
	☐ The person(s) I care for did not want to use services						
	Other, please describe:						
	None of the above						
	Please leave any comments you might have on your experience with mental health services:						
prac	following questions are about when the person you care for accesses health services, including a general titioner (GP) or family doctor, community health services and services within a hospital. Please indicate how much						
34.	How much do you agree with the following statements?						
	** **I						

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
When I accompany the pers	on I care for	to visit a GP	···			
l am asked about my needs as a carer						
I am provided with all the information I need						
When I accompany the pers	on I care on a	a visit to the	hospital or co	mmunity hea	Ith service	
l am asked about my needs as a carer						
I am provided with all the information I need						
there are sufficient support options and facilities for carers (e.g. seating, overnight rooms, transport support)						

Which of the following carer support services do you currently use? Which would you like to use more?		
Support type	I am currently using this support	I would I to use t support n
Carer peer support (face to face carer support groups)		
Online forums or groups		
In-person carer counselling (counselling designed specifically to address challenges relating to the caring role)		
Carer counselling over the phone		
Carer coaching or mentoring (working on personal goals and resilience relating to the caring role, one-to-one)		
Emergency respite (care in a facility or in the home provided when you are suddenly unable to provide care for a period of time)		
Planned respite (care in a facility or in the home booked in advance so that you are able to participate in other activities or take a longer break from caring)		
Carer specific online information or training courses		
Carer specific face-to-face information sessions or workshops		
Other, please specify:		
Have you heard of the Carer Gateway?		
 No Yes, and I have used it (e.g. called the 1800 number, visited the website Gateway Service Provider in my local area) 	e, accessed service	es from a Car
Yes, but I have not used it		

38. How much do you agree with the following statements:

In ever get time out from my caring responsibilities I am able to take just enough time out from my caring responsibilities to keep going I am able to take just enough time out from my caring responsibilities to keep or for the responsibilities, e.g. household chores I am able to regularly take enough time out from my caring responsibilities, e.g. household chores I am able to regularly take enough time out from my caring responsibilities to properly relax and recuperate I am able to take enough time out from my caring responsibilities to pursue my own goals and interests When I have time away from my caring responsibilities I am still constantly thinking about the needs of the person I care for Have you experienced any of the following challenges with carer support services? Please tick all that a The services received was at a lower level than what was required There was a long waiting period to access services The services available did not meet my needs (e.g. available when I needed them) There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity) I was concerned about the quality or safety of the services available in the control of the control of the services were available and how to access them It took too much time and energy to organise the services were available and how to access them It took too much time and energy to organise the services were available and how to access them It took too much time and energy to organise the services There is not enough transport to the services to help me i		Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
ana able to take just enough time out from my caring responsibilities to teep going Iam able to take just enough time out from my caring responsibilities to keep on top of other responsibilities, e.g. Iam able to regularly take enough time out from my caring responsibilities to properly relax and recuperate Iam able to take enough time out from my caring responsibilities to pursue my own goals and interests When I have time away from my caring responsibilities I am still constantly thinking about the needs of the Description of the services of the Description of the services are along waiting period to access services These revices a vailable did not meet my needs (e.g. available when I needed them) There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity) I was concerned about the quality or safety of the services available I he control to find information about what services were available and how to access them It took too much time and energy to organise the services I don't see myself as a carer My caring role is a private matter The person I care for does not think I need or want services I don't see myself as a carer My caring role is a private matter The person I care for does not think I need or want services I do not want or need any or more services to help me in my care role							
enough time out from my caring responsibilities to keep on top of other responsibilities, e.g., household chores I am able to regularly take enough time out from my caring responsibilities to properly relax and recuperate I am able to take enough time out from my caring responsibilities to properly relax and recuperate I am able to take enough time out from my caring responsibilities to pursue my own goals and interests When I have time away from my caring responsibilities I am still constantly thinking about the needs of the person I care for Have you experienced any of the following challenges with carer support services? Please tick all that a The service received was at a lower level than what was required There was a long waiting period to access services The services I needed were not available locally The services available did not meet my needs (e.g. available when I needed them) There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity) I was concerned about the quality or safety of the services available The cost of services (including co-payments) was too high It was difficult to find information about what services were available and how to access them It took too much time and energy to organise the services I don't see myself as a carer My caring role is a private matter The person I care for does not think I need or want services I do not want or need any or more services to help me in my care role	enough time out from my caring responsibilities to						
enough time out from my caring responsibilities to properly relax and recuperate I am able to take enough time out from my caring responsibilities to pursue my own goals and interests When I have time away from my caring responsibilities I am still constantly thinking about the needs of the person I care for Have you experienced any of the following challenges with carer support services? Please tick all that a The service received was at a lower level than what was required There was a long waiting period to access services The services I needed were not available locally The services available did not meet my needs (e.g. available when I needed them) There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity) I was concerned about the quality or safety of the services available The cost of services (including co-payments) was too high It was difficult to find information about what services were available and how to access them It took too much time and energy to organise the services I don't see myself as a carer My caring role is a private matter The person I care for does not think I need or want services I do not want or need any or more services to help me in my care role	enough time out from my caring responsibilities to keep on top of other responsibilities, e.g.						
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my caring responsibilities I am still constantly thinking	time out from my caring responsibilities to pursue						
Have you experienced any of the following challenges with carer support services? Please tick all that a The service received was at a lower level than what was required There was a long waiting period to access services The services I needed were not available locally The services available did not meet my needs (e.g. available when I needed them) There were no culturally appropriate services available (e.g. accommodating for cultural background, language spoken, or gender identity) I was concerned about the quality or safety of the services available The cost of services (including co-payments) was too high It was difficult to find information about what services were available and how to access them It took too much time and energy to organise the services I don't see myself as a carer My caring role is a private matter The person I care for does not think I need or want services I do not want or need any or more services to help me in my care role	my caring responsibilities I am still constantly thinking about the needs of the						
I don't see myself as a carer My caring role is a private matter The person I care for does not think I need or want services There is not enough transport to the services I do not want or need any or more services to help me in my care role	The service received was a There was a long waiting p The services I needed were The services available did There were no culturally a language spoken, or gence I was concerned about the The cost of services (included) It was difficult to find infor	at a lower leve period to acce re not available not meet my r ppropriate ser der identity) e quality or saf ding co-payme	I than what was services e locally needs (e.g. a vices available) fety of the seents) was too what service	vas required vailable when le (e.g. accommented available high s were available	I needed then modating for (n) cultural backgr	
I can't organise another carer or respite to take enough time out	I don't see myself as a car My caring role is a private The person I care for does There is not enough trans I do not want or need any Service providers think the	er matter s not think I ne port to the ser or more service person I care	ed or want s vices ces to help n for is the or	ervices ne in my care ro nly one who neo			

SECTION 4: PAID WORK

40.	Which of the following have you experienced as a result of your caring role? Please tick all that apply.
	☐ I have lacked the knowledge and confidence to apply for jobs effectively
	☐ My skills or qualifications have become out of date due to time out of the workforce
	☐ I feel less prepared to meet the demands of my job
	☐ I have worked in a job lower than my skillset
	☐ I reduced my working hours
	☐ I changed industry/occupation
	☐ I turned down a new job or promotion
	☐ I quit working or looking for work to be able to care
	☐ I retired earlier than anticipated to be able to care
	☐ I could not find any jobs in my field that would allow me to continue with my caring responsibilities
	☐ I have been denied an opportunity by an employer
	 An employer has changed my working conditions
	□ None of the above
	Other, please specify:
41.	What is your occupation?
42.	Do you currently have a paid job?
	☐ Yes
	No, but I am looking for work (Please go to Question 49)
	No, and I am not looking for work (Please go to question 50)
43.	How many hours per week do you usually spend doing paid work?
	hours
	u have more than one paid job, please refer to your main job (i.e. where you spend the most hours) in answering following questions
44.	Which of the following apply to you?
	☐ I am a permanent employee (either part time or full time)
	☐ I have a fixed-term contract (either part time or full time)
	☐ I have a casual job
	☐ I am self-employed
	I am self-employedI am an independent contractor

If you are a former carer, and you are not **currently** providing care for someone, please go to Question 50.

45. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I have to miss caring activities due to the amount of time I must spend on my job						
I am often so emotionally drained when I finish work that it affects my ability to provide care						
The behaviours that make me effective at work do not help me to be a better carer						0
I have to miss work activities due to the amount of time I must spend caring						
Because of my caring responsibilities, I have a hard time concentrating on my job						
Behaviour that is effective and necessary for me as a carer (e.g. being compassionate) would be counterproductive at work		0		0		

46. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
The job allows me to plan how I do my work						
The job involves performing a variety of tasks						
The results of my work are likely to significantly affect the lives of other people						
The job involves performing relatively simple tasks						
I have the opportunity to develop close friendships in my job						

47. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
Being in paid work						
Helps me to understand different viewpoints and this helps me be a better carer						
Makes me feel good and this helps me be a better carer						
Helps me feel personally fulfilled and this helps me be a better carer						
My involvement in caring						
Helps me acquire skills and this helps me be a better employee						
Puts me in a good mood and this helps me be a better employee						
Encourages me to use my work time in a focused manner and this helps me be a better employee						
Which of the following flexil your caring role? Please tick Flexible start / finish times	all that apply		ts are you usin	g in your cur	rent job to ac	commodat
 Working from home Job sharing Paid personal leave (from from the state)	the 10 accrual	, ,	•	d for sick leav	e and/or carers	s leave)
 Paid carers leave in addition Unpaid carers leave (from Additional unpaid carers leave Annual leave (holidays) None of the above 	the 2 days mo	ost workers a	re entitled to)			

49. How much do you agree with the following statements?

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	N/A
I had trouble finding work,	because					
my skills weren't recognised						
it wouldn't be possible to respond to an emergency						
the type of work would have kept me from sufficiently checking on the person I care for						
the demands on time would have been too high to keep up my caring role						
there wasn't enough support for carers by the prospective employer (e.g. lack of flexibility)						
it wouldn't be possible to take enough paid leave to keep up the caring role						

SECTION 5: YOUR HEALTH AND WELLBEING

50. Please indicate how satisfied you are with each of the following:

	Completely dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10
Your standard of living											
Your health											
What you are achieving in life											
Your personal relationships											
How safe you feel											
Feeling part of your community											
Your future security											
Your life overall											

51. In the past 4 weeks, about how often did you feel:

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Nervous					
Without hope	0				
Restless or jumpy	0				
That everything was an effort	0				
So sad that nothing could cheer you up					

52. How many hours per week do you have for yourself?

"Time for yourself" is time where you can pursue activities of your choice - that are not related to caring responsibilities, work, or to household and other chores.

____ hours

53. How often have you experienced the following?

	Almost always	Most of the time	About half the time	Occasionally	Not at all
During the past four weeks					
It has been easy to relate to others					
I felt isolated from other people					
I had someone to share my feelings with					
	Almost always	Most of the time	About half the time	Occasionally	Not at all
I found it easy to get in touch with others when I needed to					
When with other people, I felt separate from them					
I felt alone and friendless					

54.	How	satisfied	are	you	with
-----	-----	-----------	-----	-----	------

55.

56.

☐ No

	Complete dissatisfie 0		2	3	4	Neutral 5	6	7	8	9	Completely satisfied 10	N/A
your relationship vith your partner?												
your relationship vith your parents?												
your relationship vith your children?												
your relationship vith your friends?												
		Strongl agree	у	A	gree	agre	ther e no gree		Disa	gree	Strongly disagree	N/A
feel that my caring		_	y	A	gree	agre	e no		Disa	gree		N/A
ecognised and value ny community	ed by						<u> </u>			<u> </u>		
feel that my caring ecognised and value ny family						C	כ		C			
feel that my caring ecognised and value ny friends						C)		C)		
feel that my caring ecognised and value ervice providers						C)		C)		
feel that my caring ecognised and value ne government						C)		C)		
feel that my caring ecognised and value ervice providers feel that my caring ecognised and value	role is role is ed by	e you ł		-	_	term illne	ss or			y tha	at has lasted, or	is li

SECTION 6: ABOUT YOU

57 .	How old are you? years old	
58.	What is the postcode where you live?	
59.	What is your gender?	
	 Female Male Non-binary / gender diverse 	
	My gender identity isn't listed. I identify as:	
	☐ Prefer not to say	
60.	What is your cultural background? (e.g., Italian, Chinese, Australian, etc.)	
61.	Do you speak a language(s) other than English at home?	
	Yes, I speak (e.g. Vietnamese, Auslan)	
	☐ No, English only	
	☐ Prefer not to say	
62.	Are you of Aboriginal or Torres Strait Islander origin?	
	□ No	
	Yes, Aboriginal	
	Yes, Torres Strait Islander	
	Yes, both	
	☐ Prefer not to say	
63.	What is the highest level of education you have completed?	
	Less than high school (year 12 or equivalent)	
	High school (year 12 or equivalent)	
	Certificate / diploma	
	Bachelor degree or higher	
	Other, please specify:	
64.	Are you currently enrolled in any formal education?	
	□ No	
	☐ Yes – high school	
	Yes – TAFE / apprenticeship	
	Yes – university	
	Other, please specify:	
65.	Do you consider yourself to be:	
	Lesbian, gay, or homosexual	
	Straight or heterosexual	
	☐ Bisexual	
	Queer	
	☐ Not listed, my sexual orientation is:	
	☐ Prefer not to say	

How confident are you... 66.

	Very confident	Confident	Somewhat confident	Not at all confident	N/A
using the internet to find information about caring					
using the internet to access online support services					
using the internet to stay in contact with friends and family					

67 .	What is your	household's	s yearly income	(before tax)
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	information about caring								
	using the internet to access online support services								
	using the internet to stay in contact with friends and family								
67.	What is your household's yearly in	ncome (befor	e tax)?						
	Please include your partner's and / c investment income). Please tick you	•	7 1	come from all sc	ources (e.g. wag	jes, pension,			
	Up to \$9,999 per year (\$1 - \$1890) \$10,000 - \$19,999 per year (\$190) \$20,000 - \$29,999 per year (\$380) \$30,000 - \$39,999 per year (\$580) \$40,000 - \$49,999 per year (\$770) \$50,000 - \$59,999 per year (\$770) \$60,000 - \$79,999 per year (\$1,10) \$80,000 - \$79,999 per year (\$1,50) \$100,000 - \$124,999 per year (\$1,50) \$125,000 - \$149,999 per year (\$1,50) \$150,000 or more (\$2,880 per weight per year (\$1,50) Prefer not to say		veek) veek) veek) r week) per week) per week)						
68.	Including you, how many people are living in your household?								
	Children under the age o	f 15							
	Children aged 15 to 18								
	Adults aged 18 to 64								
	Adults aged 65 and older								
69.	Do you receive any payments from	n Centrelink'	? Please tick all	that apply					
	Carer Allowance (currently \$131.90 per fortnight)								
	Carer Payment (currently up to \$933.40 per fortnight for singles and \$1,407.00 for couples)								
	Newstart Allowance								
	☐ Age Pension								
	Disability Support Pension								
	Commonwealth Rent Assistance								
	Other, please specify								
	☐ I don't know								

69.	Do you receive any	payments from Centrelink?	Please tick all that apply
-----	--------------------	---------------------------	----------------------------

Carer Allowance (currently \$131.90 per fortnight)
Carer Payment (currently up to \$933.40 per fortnight for singles and \$1,407.00 for couples
Newstart Allowance
Age Pension
Disability Support Pension
Commonwealth Rent Assistance
Other, please specify
I don't know
None of the above

You would have been unable to raise \$2,000 in a week for something important
You could not pay rent or mortgage payments on time
You spend more money than you received in a month
You could not pay gas, electricity, water, or telephone bill on time
You could not pay registration or insurance on time
You pawned or sold something
You went without meals
You were unable to heat or cool home
You sought assistance from welfare/community organisations
You sought financial help from friends or family
None of the above
id you need to pay for any of the following for the person(s) you care for at least once in the last 12 nonths?
Medicine
Support services
Transport (including parking)
Insurance
Housing
Housing modifications
Special training
Health services and equipment
Other, please specify:
None of the above
re you a member / affiliate member of, or registered with, the Carers Association in your state or erritory (e.g. Carers NSW, Carers WA)?
Yes
) No
Don't know

You have finished the survey - thank you for your input!

Remember, if you feel upset or have any concerns about anything from this survey, we strongly encourage you to call the Carer Gateway (1800 422 737, open Monday to Friday, 8am to 5pm), which will offer support and carer specific services in your area.

If you are in distress, please call Lifeline (13 11 14, open 24 hours, 7 days), or contact your local GP (https://www.healthdirect.gov.au/australian-health-services). In an emergency, please call 000.

If you wish to contact an Aboriginal or Torres Strait Islander Health Service, please contact the service nearest to you. A list of services is available under https://healthinfonet.ecu.edu.au/key-resources/health-professionals/health-workers/map-of-aboriginal-and-islander-healthmedical-services/.

74.	OPTIONAL: Please participate in the follow-up study in 2022 and help us track the impact of caring
	over time!

	over time.
	If you agree to participate, we will contact you for the next carer survey in 2022. Your answers will be assigned a randomly generated unique identifier, allowing a comparison over time. No information identifying you personally will be stored in the dataset. Please refer to the accompanying Participant Information and Consent Form for details.
	Yes I would like to participate in the follow-up study!
	Please provide your contact details below.
75.	OPTIONAL: As a thank you for participating in the survey, you can win an Apple iPad 32GB Wi-Fi!
	The prize will be drawn on 30 July 2020, the winner will be contacted via email.
	☐ Yes I would like to participate in the prize draw!
	Please provide your contact details below.
	I want to participate in the follow-up study and/or the prize draw. My contact details are:
	Name
	Email
	Street address