

# Carers, We See You

## UTS STUDENT CONSULTATION REPORT

Exploring the experiences of student carers at UTS





UTS: DESIGN  
INNOVATION  
RESEARCH CENTRE



UTS acknowledges the Gadigal People of the Eora Nation and the Boorooberongal People of the Dharug Nation upon whose ancestral lands our campuses stand. We would also like to pay respect to Elders past and present, acknowledging them as traditional custodians of knowledge for these Lands.

This project was a collaboration between the UTS Centre for Carers Research, Centre for Social Justice and Inclusion (Equity and Diversity Unit), Carers NSW Australia and the UTS Design Innovation Research Centre (DIRC).

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# Executive Summary

A carer provides ongoing, unpaid help to someone who needs it because of a disability, long-term or life limiting illness, mental illness, dementia or ageing. Research by Carers NSW reveals that carers, particularly young carers, commonly report lacking support from institutions regarding flexibility to assist them to balance their studies with their caring responsibilities. There are approximately 44,000 carers in NSW currently attending university, with just under half (45%) aged under 24 years.

This consultation aims to better understand the everyday experiences and challenges faced by UTS student carers, and develop ways that the university could better support student carers to achieve a better balance in their life as both a student and carer.

The Centre for Carers Research carried out this research in collaboration with the UTS Design Innovation Research Centre, the UTS Centre for Social Justice and Inclusion, and Carers NSW. The consultation involved two focus group discussions with five student carers and two focus group discussions with seven UTS staff Academic Liaison Officers (ALO) – Faculty based staff who have responsibility for assisting student carers. Subsequent design synthesis led to the creation of a set of principles that could underpin and influence

the character of any university interventions, a number of insights on the student carer/staff population, and a series of suggestions for UTS to consider implementing to better support the student carers of the University, and the staff tasked with supporting them.

The key principles included: providing increased flexibility in university process and interaction towards unique student carer circumstances as they may arise, embedding more humanity in the system, and raising the visibility of student carers amongst the university community.

## Key insights included:

- Student carers feeling like they did not have enough support and knowledge of how to navigate University services in times of crisis,
- The need for less repetition of paperwork for exemptions and special considerations,
- The need for greater awareness and data of the student carer population at UTS,
- The need to better connect with other carers within the University,
- Recognising the positive skills and attributes that student carers possess to be able to carry out this crucial caring support on top of their own lives, and

- The need to better support ALO staff to deal with emotionally and charged situations.

## Suggestions for UTS covered four main areas:

- **Products:** such as a carers card and a welcome pack would help student carers' understanding of the resources and services available to them within the University and reduce repetition of paperwork for exemptions.
- **People:** includes the development of a supportive carers network, a carer's retreat, and more face-to-face empathetic interaction with the University.
- **Process:** recommendations include the establishment of a student carer registration and data collection process at enrolment for greater support and knowledge of the carer community, clearer progress/feedback loops when interfacing with the system, and a communications plan to build on stories and visibility of student carers amongst the UTS community.
- **Policy:** includes better involving carers in the co-development of university policy, as well as creating procedural flowcharts in language accessible to students.

# Background

USING DESIGN THINKING TO  
UNDERSTAND THE EXPERIENCES  
OF STUDENT CARERS



# Introduction

## About this document

This report is intended to be read by a general audience within UTS, from students to strategic decision makers. It provides a snapshot of both the challenges and capabilities of the student carer population at UTS, and suggestions for opportunities to better support them. These opportunities are by no means exhaustive or final; they are provocations intended for discussion and development within the University community.

The Centre for Carers Research was established in 2018 with a research grant from The NSW Department of Communities and Justice (formerly Family and Community Services). The Centre works collaboratively on applied and action research projects to provide high quality evidence for effective policy and programs for carers. The Centre works in close partnership with the NSW peak organisation, Carers NSW.

The UTS Design Innovation Research Centre (DIRC) uses a design-based action research approach to projects. Research is carried out in a collaborative and practical way with both project partners and research participants. Design research attempts to understand the deeper human needs and values that drive behaviour, and provoke others with new ideas to address issues. The UTS Centre for Social Justice and Inclusion is the gateway by which community organisations, not for profits, social purpose businesses and individuals may engage with the University's resources and expertise to maximise

social impact. The Equity and Diversity Unit within this Centre promotes a diverse, inclusive and accessible university environment.

In line with the UTS Social Impact Framework\* this consultation explores the student carer population at UTS, to understand their everyday experiences and challenges, and develop ideas and suggestions about how the university might better support them to achieve an improved balance in their life as both a student and carer. It should be noted that this consultation is only the first step in a larger project and involved only a small sample of student carers and UTS staff who support them. As such, it aims to offer some insights on which further consultation and co-design of carer support initiatives might be built.

According to research by peak body, Carers NSW, there are approximately 44,000 carers in NSW currently attending university, with just under half (45%) aged under 24 years. Carers, particularly young carers, commonly report lacking support from institutions regarding flexibility in assisting them to balance their studies with their caring responsibilities. These numbers are likely understated, as research indicates that many people in caring roles do not identify as carers and as such are frequently not linked to services

and supports that can assist them. UTS does not keep centralised records of student carers, so the exact number of those with caring roles is unknown.

The legislated definition under the NSW Carers (Recognition) Act 2010, is that a carer is someone who provides ongoing, personal care, unpaid support and assistance to a person who needs it because of disability, mental illness, a medical condition, chronic or terminal illness, dementia or frail age. Relatives and friends who provide such care, support and assistance are carers.

Under the NSW Carers (Recognition) Act, public sector agencies including academic institutions must ensure that staff and agents of the agency have an awareness and understanding of the NSW Carers Charter. Public sector agencies must consult with carers or bodies representing carers when developing policies that impact upon carers. The internal human resources policies of public sector agencies must be developed with due regard to the NSW Carers Charter. **While the Act does not give carers legal rights, entitlements or status, it does create obligations for public service agencies including academic institutions to improve the degree to which they recognise, include and support carers.**

# Consultation

In exploring the experience of student carers at UTS The Centre for Carers Research carried out this consultation in collaboration with the UTS Design Innovation Research Centre, and the UTS Centre for Social Justice and Inclusion. Underpinning the consultation was the research and policy work provided by the Carers NSW Policy and Research team. The project involved:

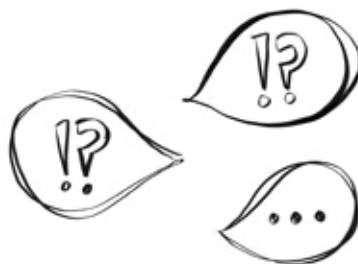
## A process and policy review:

Informal interviews with key stakeholders in student carer support across UTS, to understand the processes, policies and support services available to student carers.



## Student focus group discussions:

This included a callout to the UTS student carer population via internal channels, and then exploring with students, the experiences of life as a student and carer and possible opportunities for better support from the university. We spoke, in depth with five student carers from a diverse range of backgrounds.



## Academic Liaison Officers (ALO) focus group discussions:

Faculty based ALOs are frequently the first point of contact for students experiencing difficulties with their studies because of their caring responsibilities. In two focus group discussions with seven ALOs we explored their experience of supporting student carers and their ideas about how this support could be further improved.

## Design synthesis:

To draw together insights and ideas for further university consideration. Some overarching principles emerged to help guide the UTS response.





# Insights



# Emerging Principles

Some pertinent design principles have emerged from the consultation discussions. These principles could potentially scaffold further strengthening of the student carer support processes and response. They are intended to ensure initiatives are human-centred and student-focused, and guide individuals who are developing and implementing them. Looking ahead, these principles may be useful in evaluating the effectiveness of student carer initiatives implemented by the university.

While specific to the UTS context, these emerging principles also align to principles outlined in the *NSW Carers (Recognition) Act 2010*, including *acknowledging and recognising the uniqueness and diversity of carer experiences and knowledge in policy and service delivery, and that support for carers should be timely, responsive, accessible and appropriate.*



“If I kept asking for extensions  
I’d never get it done”  
– STUDENT

“People don’t have to live with you for  
you to be always thinking about them”  
– STUDENT

## Increasing flexibility

Each person’s caring role is different and sometimes unpredictable. Student carers are often taken away from their university responsibilities to deal with unplanned, episodic instances of their caring responsibilities. UTS could provide greater opportunities to adapt and accommodate to these individual needs in the support provided.

“My world has become so small...  
there’s only so much you can talk  
about...I often feel isolated”  
– STUDENT

# Principles



## Visibility of carers

Little is known about the student carer community at UTS. Carers themselves do not always self-identify, or are reluctant to share their experiences with others or the university. To better support student carers UTS could focus on raising awareness of the student carer community, and empower individual student carers to champion their unique skills and situation.



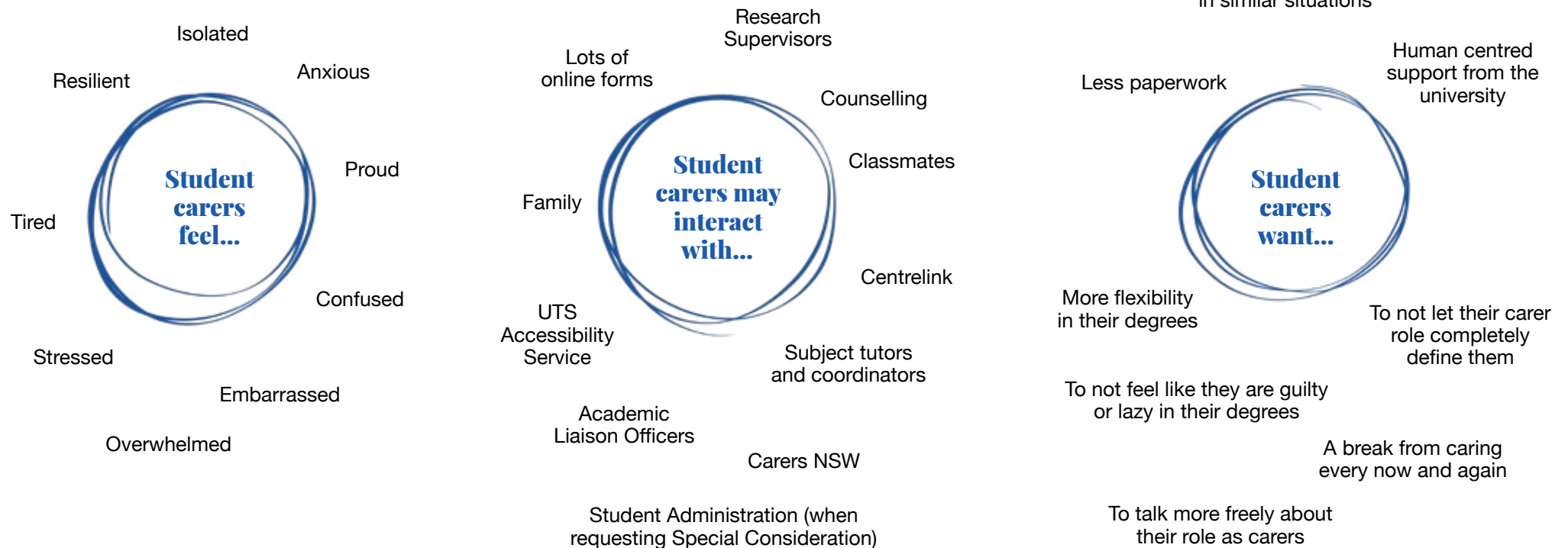
## Further humanising the system

It was reported by student carers and ALOs that it can be difficult for student carers to navigate the university systems and feel supported, particularly in times of crisis. UTS could work with staff or student carers to consider how support services can respond in more consistently empathetic ways.

The UTS Social Impact Framework provides a useful scaffolding for the principles and findings from this consultation. While little data on student carers is collated by UTS, anecdotal reports and research evidence suggests that caring responsibilities are likely a reason for dropping out of university, thus impacting UTS retention rates. Student carers and staff tasked with responding to student carers needs, have crafted practical and effective suggestions to strengthen their agency to better enable their caring and greater social responsibilities, all the while maintaining academic integrity and success. The research collaboration has relied on cross disciplinary and community contributions to address a social issue – that of caring responsibilities and roles as a universal part of human experience. This consultation and further research also offers UTS a small but important opportunity to be a leader in social change.

# Insights Snapshot

The following insights are derived from a combination of student carer perspectives, Academic Liaison Officers and other staff perspectives, and the policy review. Insights will often have anonymous supporting quotes direct from the consultation, and suggested ideas for how the university might consider addressing them. These suggestions are collated and described in a later section of this report.



# Insights & Suggestions

## Student carers can often feel overwhelmed when engaging with the university

“We need a carer champion to deal with carer responsibilities”  
– STUDENT



“My peers party and have fun, find themselves, and I’m envious because I can’t even talk about it”  
– STUDENT

In times of crisis, which are usually unplanned and episodic in nature, carers are highly stressed and confused as to where to seek support and guidance in the university. The anxiety of the possibility of failing and having to drop out of university is frequent in a carer’s life.

Student carers tend to only access university support services at a crisis point (at a time when they are at their most vulnerable), which increases the weight of stress on the students, staff and system processes. It also frequently increases time pressures involved in putting supports in place.

- The university could develop a welcome pack for carers, which is written in an easy, empathetic tone, which provides clear guidance on who to talk to in need, the university’s carer policies, and other resources. There could also be a central place for holding these resources.
- The university could consider a carer mentorship model, where other student or staff carers can be a point of contact for advice and guidance.
- ALOs suggested that UTS could, more consistently, (across faculties) offer more flexibility in how subjects and courses are offered, such as alternate assessments in the case of a carer not being able to complete work in time.
- The university could consider more uniformly strengthening mechanisms to sit and proactively plan with student carers early in semester, mapping their needs and pre-planning options in case of an incident.

“If I just had a simple flowchart of what’s available, who to go to”  
– STUDENT

“My focus isn’t great when I have to juggle these responsibilities”  
– STUDENT

“The system feels so complicated; I don’t understand it”  
– ALO STAFF

“I feel bruised...so tired”  
– STUDENT

## Insights & Suggestions

### Student Carers can often feel overwhelmed when engaging with the university

“It’s embarrassing to ask for exemptions”  
– STUDENT

“I’ve read the policies...there’s no connections between university policy and the practice”  
– STUDENT

Some student carers reported feeling a lack of flexibility and empathy from the university. Repeatedly explaining their caring responsibilities and filling out forms for exemption and/or special consideration are an extra burden on student carers. They also reported feeling that the communication and feedback during and after interactions with these processes could be improved.

Some student carers report that they don’t know how or where to access UTS support systems and policies. Others reported that their experience with the implementation of UTS carer policies could be made more empathetic.

“I’d rather just hand in an assignment and lose a percentage of it than go through the paperwork”  
– STUDENT

- UTS could develop a carer’s card, similar to the LEAP program for elite athletes, which could provide extra access and benefits for student carers, and reduce the need for repetitive form filling and re-describing their situation.
- UTS could consider creating more processes based on face to face interaction between carers and the university, reinforcing human points of contact in the system.
- UTS could use more empathetic language in their written communications with student carers requesting special considerations.

- UTS could consider reviewing policy and grievance/exemption documentation for greater empathy. Students suggested clear flowcharts and language that is easy for carers to access and understand. This could also be designed to aid staff in understanding carer procedures.
- Policy could be co-designed with student carer representatives.
- UTS could consider holding information sessions for student carers.
- Carers NSW could have more of a presence at UTS, and be more involved in co-developing university policy and action.

“[I] feel like a KPI, not a real person”  
– STUDENT

“[There was] no acknowledgement of what happens after I’ve put in exemptions”  
– STUDENT

# Insights & Suggestions

## Student carers can often feel overwhelmed when engaging with the university

“There is a growing attitude that academics think that students are scamming the system, which is unfair”  
- ALO STAFF

Some staff and students reported that, unlike processes in the UTS Accessibility Service, there does not seem to be a consistent and clear process for student carers at UTS.

- UTS could consider more clearly defining and communicating to the UTS community, who can access and how to access support for student carers.

“Where does responsibility for carers sit?”  
- STUDENT

“The experience is quite extreme for me...the approach of the student really matters”  
- ALO STAFF

There is a perception that attitudes towards student carers amongst some teaching staff may be hardening in their responses to care requests for considerations and exemptions. It was also suggested that the culture of some teaching staff may be less flexible as student cohort sizes increase. These attitudes can be harmful to student carers already going through emotional times. Both students and ALOs had positive experiences with UTS Counseling.

- More cohesive student carer support would allow students to more easily present proof of their carer status and need for consideration.



## Insights & Suggestions

### Staff supporting student carers

“As an ALO, whether to step in or not?  
To contact the student in advance of next semester or leave it for them to contact me”  
- ALO STAFF

“The emotional state of the student when they come to you...I am not sure I have the expertise to deal with to give the student proper support”  
- ALO STAFF

**Academic Liaison Officers (ALO) are intended to be a key point of contact for carers, however little is known about them from the student perspective.**

**ALOs can help to mediate the emotional issues of a carer and inform them of what support is available within the UTS system, although they acknowledge this is a huge emotional load to carry.**

**ALOs indicated the difficulty of managing their current roles even without the consideration of student carers, dealing with issues such as mental health, wellbeing, disability and special consideration, on top of their regular workload.**

**ALOs indicated that more consistent training and new skills such as counselling and mental health first aid would help them more effectively deal with carer issues.**

**ALOs also indicated that there is no consistency in tracking carers at UTS.**

**Non ALO teaching staff, who may not be aware of the appropriate services available, are often first points of reference for student carers who are seeking help.**

“My supervisor was my first port of call”  
- STUDENT

“Sometimes you feel you want to do more, but how can you carve out more time, given the allocation we are getting”  
- ALO STAFF

“I should probably have a register, because I have people at all different phases”  
- ALO STAFF

- UTS could consider better training, reward and recognition of the work of ALOs, especially in how to better deal with emotionally draining situations, caring for both the student and themselves.
- ALOs are part of a network coordinated by the Accessibility Team and supported by UTS Counselling. There was a perception that this network could be strengthened or more consistently applied across faculties.
- UTS could consider whether a carer representative or champion (from the Student Association for example) could be helpful as a focal point for student carers to interact with carer support processes.



# Insights & Suggestions

## Little is known about the student carer experience



“In postgraduate research, there are no accommodations”  
- STUDENT

There is currently no registration and data collection process for student carers at UTS.

- UTS could consider establishing a clear, simple option for students to register as a carer at enrolment, at orientation, and/or yearly through their degree, should circumstances change.
- UTS could consider specific supports for postgraduate carers.

ALOs had the perception that some faculty staff are not aware of carers responsibilities and the issues they face. They suggested that a UTS carer awareness program may help with this.

- UTS could work with staff in faculties to sensitise them to the nature of the issues faced by carers, and where they might be able to direct them. This could be as simple as orienting them to the role of ALOs.

“People are reluctant to say anything [about being a carer], and often it is then too late”  
- ALO STAFF

There is currently an onus on a student to self-identify as a carer. Students don't often readily self-identify due to stigma and embarrassment, as well as not wanting it to be their defining role. Challenges associated with registering as a carer in other circumstance, such as Centrelink services, can be a barrier to identifying as a carer in other forums, such as at UTS.

This then makes it harder for students to be made aware of, and receive, appropriate and timely support from UTS should they need it. It also makes it harder for others (both students and staff) to understand the heavy emotional load carers often carry.

“I think some students don't register because they think they need to reach the same threshold [as Centrelink]”  
- ALO STAFF



# Insights & Suggestions

## Student carer skills

“I’ve learnt so much from the person I care for”  
- STUDENT

“I find that carers have the most amazing time management”  
- ALO STAFF

“There are skills you don’t know you had”  
- STUDENT

Often the focus on carers is on the challenges and hardships they experience, and less on the positive traits needed and built during their experiences. Skills such as empathy, patience, organisational and advocacy skills, humour and resilience are critical to balance student and carer life.

- Mindful of their time (or lack thereof), carers could mentor or educate others in the university in how to develop these traits.

- UTS could consider developing a communications plan to raise the visibility of carers, for both carers themselves, and the wider UTS community. Acknowledging and sharing stories of the strengths and resilience of the carers could help breakdown some stigmas associated with carers. These stories could be celebrated during Carers Week in October every year and be used in other UTS student forums.

“The impact of looking after a sibling is a whole different world...it’s always with you”  
- STUDENT

“I struggle with the word carer...I’m a mother, daughter, friend, wife”  
- STUDENT



# Insights & Suggestions

## Connecting with other carers

“I need respite just as much as they do”  
- STUDENT



“Being a carer in a uni is so isolating”  
- STUDENT

“I just want a little break sometimes”  
- STUDENT

Carers highlighted how their caring roles were often overwhelming and all-encompassing and often difficult to get away from.

They also felt it would be valuable to connect with other carers from time to time, to discuss challenges and feel like they weren't alone in their journey and role.

Student carers desired to continue to develop their relationship with UTS after they leave, and there were fears of losing this should they have to drop out of their degrees due to carer responsibilities.

Students also feel like they miss out on parts of the regular university experience because of their responsibilities.

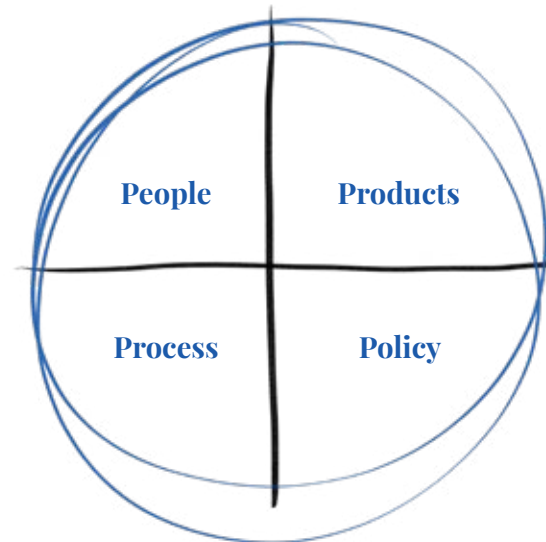
- UTS could consider establishing carer retreats to give student carers time to get away from these often exhausting roles, and to meet other people also going through similar things.
- UTS could establish a student carer network, which could combine online forums and face to face meetups. This could be about informal support/advocacy, sharing of resources and articles, asking questions and meeting up to socialise with others. This could have connections to carers in other universities and organisations. This would broaden the conversations to more than one-on-one conversations.
- UTS could consider creating safe spaces for student carers and the people they care for while on campus similar to the Student Services Unit Resource Room for students with a Disability.
- A student carer suggested UTS provide access to library and research platforms during carer's breaks in studying (arising from caring responsibilities) to assist students to maintain their study skills and increase their capacity to re-engage.



# **Ideas for how UTS could enable change**

# How UTS can further support student carers

The following is a collated list of possible opportunities which can be further developed at UTS to better support the student carer population. These have been scattered throughout this report, often in response to a direct need or insight from the consultation. These are not intended to be final or the only solutions to the issues highlighted in the this report, but discussion points to be further built upon with relevant UTS stakeholders. They have been grouped here according to four key categories, namely Products, People, Process, and Policy.



**“Whatever system we develop, there must also be the flexibility to provide for all types of people”**

## How UTS can further support student carers

### Products

- UTS could develop a welcome pack for carers, which is written in an easy, empathetic tone, which provides clear guidance on who to talk to in need, UTS carer policies, and other resources.
- UTS could develop a carer's card, similar to the LEAP program for elite athletes, which could provide extra access and benefits for student carers, and reduce repetitive form filling and re-description of the problem to others in the university.
- UTS could consider holding information sessions for carers.
- UTS could consider creating safe spaces for student carers and the people they care for while on campus similar to the Student Services Unit Resource Room for students with a Disability.



# How UTS can further support student carers

## People

- UTS could consider more face-to-face interaction between carers and the university, reinforcing human points of contact in the system.
- UTS could consider a carer mentorship model, where student or staff carers can be a point of contact for advice and guidance for others.
- UTS could consider whether a carer representative or champion (from the Student Association for example) could be helpful as a focal point for student carers to interact with carer support processes.
- Mindful of their time (or lack thereof), carers could mentor or educate others in the university in how to develop these traits.
- UTS could establish a student carer network, which could be combination of online forums and face-to-face meetups. This could be about informal support/advocacy, sharing of resources and articles, asking questions and meeting up to socialise with others. This could have connections to carers in other universities and organisations. This would broaden the conversations to more than one-on-one conversations.
- UTS could consider establishing carer retreats to give student carers time to get away from these often exhausting roles, and to meet other people also going through similar things.
- An improved support network for ALOs to discuss issues could be developed.
- UTS could work with staff in faculties to sensitise them to the nature of the issues faced by carers, and where they might be able to direct them. This could be as simple as orienting them to the role of ALOs.



## How UTS can further support student carers

### Process

- UTS could consider establishing a clear, simple option for students to register as a carer at enrolment, at orientation, and yearly through their degree, should circumstances change.
- UTS could consider how it incorporates greater support for postgraduate carers.
- UTS could offer more flexibility in how subjects and courses are offered, such as a 2<sup>nd</sup> assessment tool in the case of a carer not being able to complete work in time.
- UTS could consider establishing more meaningful and transparent feedback and progress loops between student carers seeking special considerations and and UTS processes/services.
- UTS could consider more clearly defining and communicating to the UTS community, who and where to go to with student carer support needs.
- UTS could consider establishing mechanisms to sit and proactively plan with student carers early in semester, mapping their needs and some directions in case of an incident.
- UTS could consider better training, reward and recognition of the work of ALOs, especially in how to better deal with emotionally draining situations, caring for both the student and themselves.
- UTS could consider developing a communications plan to raise the visibility of carers, for both carers themselves, and the wider UTS community. Acknowledging and sharing stories of the strengths and resilience of the carers that walk amongst our community could help to breakdown some stigmas associated with carers. These stories could be celebrated during Carers Week in October every year and be used in other UTS student forums.
- UTS could continue to allow access for carers to services such as the library and research platforms (Scholarx, Endnote) after they drop out or have a break in their studies due to carer responsibilities.



# How UTS can further support student carers

## Policy

- UTS could consider reviewing student carer policy and grievance/exceptions documentation to ensure that the language is appropriately empathetic. Flow charts of the support services could be developed.
- Policy could be co-designed with student carer representatives.
- Carers NSW could have more of a presence at UTS, and be more involved in co-developing university policy and action.





## Next steps

This consultation report is the first output of a broader research project, the other part of which will be a student carer best practices review across Australian and international universities. This more extensive research report will be available by the end of 2019.

This consultation offers UTS a small but important opportunity to be a leader in social change. In considering the adoption of these suggestions and ideas, UTS could be positioned to be a leader in supporting and graduating student carers. The actions coming from this consultation align with the UTS Social Impact Framework domains of focus that:

- students have the agency to enact personal and social responsibility;
- targeted research outcomes have a social impact and contribute to communities and;
- UTS is an advocate on issues that concern and impact communities.

This preliminary deep-dive provides a baseline understanding of the experiences of student carers at UTS. A further concise longitudinal study (using methods such as autoethnography and journey mapping) of a small group of carers, could help measure and track the impacts of any interventions and principles implemented by UTS to better support carers. It could also provide more granular, longer-term data, and help build a collection of stories that could help create the narrative of student carers and their roles, responsibilities, successes and hardships. It would also aid in empowering carers to reflect on their caring roles themselves, and further demonstrate to them the university's commitment to supporting student carers.

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