**Designing the New Integrated Carer Support Service**

**About Suncare**

Suncare Community Services Ltd has been operating Commonwealth Respite and Carelink Centres (CRCC) in Brisbane North and Central Queensland since 2003. Funding program contributions to these CRCCs include:

* National Respite for Carers Program (NRCP)
* Short term and Emergency Respite
* Consumer Directed Respite Care
* Mental Health Respite
* Young Carers Program
* Respite for Carers of Young People with Severe and Profound Disability
* Flexible Respite

Previous funding programs included Respite for Working Carers (now Commonwealth Home Support Program) and Carelink Information Services (now the My Aged Care Program and Community Access Point).

Suncare has many decades of experience providing carer support services, particularly with respite care, and recently with support planning through the My Aged Care Regional Assessment Service.

**Awareness**

**Question:**What would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?

**Suncare’s Response:**As well as format, content and accessibility, information disseminated to carers must be seen to be from a trustworthy and reliable source. Carers are likely trust others who are experiencing similar issues, eg personal testimonies from other carers can be very effective and encouraging.

It is important that a new carer is invited to participate in a peer discussion about what support services are available and how to access them.  Often carers may search for this information and peer support online; due to the many digital options now available it is important that a new carer can access trusted peer support early in their caring role.  However, the need for such support may decrease as the carer becomes more confident navigating the new integrated carer support service.

While fellow carers are likely to offer free support to new carers, professional online services would provide a coordinated approach to information delivery.

Another key aspect is identifying ‘hidden’ carers - those who may not identify themselves as carers. This could be achieved by disseminating information through schools, health systems, community groups, church groups, as well as cultural events such as NAIDOC, and multicultural festivals, etc.

Awareness must start with everyone in the community. Carers would benefit from having the ability to access information in their own time and in a way that suits them, such as dedicated online sites and social media, phone access to information and services, or alternatively, expos, stalls at shopping centres, and mobile buses, etc.

**Question:***Should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than in school?*

**Suncare’s Response:**While the healthcare sector is the key stakeholder for both new and longer-term carers, a coordinated approach is essential to target young carers in particular where traditional approaches to raising awareness may not be as effective.

It is important that the education system continues to play an active role in identifying and referring young carers, as many may not be identified through the healthcare system. Digital resources, including apps, could be used more effectively to inform and educate young people about support services for their caring role. School guidance officers (counsellors) and chaplains are also better placed to identify young carers and provide them with information and support to connect with the integrated carer support service.

**Information Provision**

**Question:***Would individualised recommendations be of benefit when carers are undertaking or receiving other services?*

**Suncare’s Response:**All carer situations are unique, therefore information provided to carers would be a combination of generalised and individualised recommendations.  New carers, for example, may not know where to seek out relevant information or be aware of what services are available.

A sound strategy would incorporate information sharing and referrals between service providers, although the full scope of an integrated carer support model may not be readily available in other services, and the unique carer situation may not be considered.  However, it is important that other service providers refer carers to where and how they can access more comprehensive and individualised information about their carer needs.

Resources for service providers, health care professionals, education system, etc is critical to ensure carers are registered before reaching a crisis point. These support systems are key to ensure there is an uptake for carers to register with the gateway.

**Intake**

**Question**:  *Are there ways to make intake a more beneficial process for carers?*

**Suncare’s Response**:  A variety of user friendly options would benefit carers when they start receiving support services, ranging from a centralised database to minimise duplication, a more streamlined registration process and online self-service facility, and accessible emergency contact point.

At Suncare Community Services we have replaced ‘intake’ with ‘customer service’ to reflect the ethos of client directed services. In addition, we have provided a 24/7 emergency telephone service for the past eight years to meet carers’ needs. A recorded message screens non-urgent calls before any immediate response, to maximise the efficiency of this service.

The intake process is crucial; it is acknowledged as a challenging process for carers as they are required to provide information several times. This process can be confronting for carers to face the reality of the situation they are in: It can be emotional because it presents a life changing situation; or they may be grieving a loss of lifestyle or opportunity.

The following key points for the intake process are important:

1. Connect carers to the available services they require.
2. Provide carers with choices about how they manage the process, eg they may request assistance to complete the registration, complete a self-registration online, or choose to update their details online.

An online self-registration process would help the carer feel more in control of their process and ensure the information is accurate and transparent. The online registration form must be well designed, free from jargon and user friendly. An online self-service facility would also allow the carer to update changes to circumstances as well as emergency plans, etc.

A centralised database for both the Carer Gateway assessment services (see recommendation in Needs Identification and Planning) and Carer Support Services would also limit duplication, time and stress on the carer during the intake process.

In 2015 Suncare surveyed more than 700 carers registered with Commonwealth Carer Respite Centres across five regional locations. Their feedback indicated a need for uniform access to carers’ information to avoid duplication.

**Question:***When should intake be a mandatory process?*

**Suncare’s Response:**Suncare does not support a mandatory registration (intake) process for carers. While optional, we believe in actively promoting the benefits of registration to carers, including:  provision of information to carers, linking them with support services when needed, monitoring changes in the carer’s circumstances, and facilitating a quick response in emergency situations.

Ideally all carers would be registered in a centralised database. When a carer’s role ends, their record would be archived in line with existing privacy legislation.

**Education**

**Question**: *How can we encourage carers to access education support?*

**Suncare’s Response**:  Suncare believes that marketing educational (and other) programs and services for carers is vitally important and is an area which been neglected and under-resourced for many years.

The Integrated Carer Support Service Intake (Customer Service) must maintain an up-to-date log of programs available to carers, whether they are available online or face-to-face.  This information would be included in carer information packs and regularly sent out to registered carers.

Free online training and education programs would allow carers to participate in their own time and may not require respite support to attend workshops. Online courses would also enable carers to proactively choose training that interests them.

One of the challenges to this process is that carers may have limited time available for training or education. The benefits of accessing education support must therefore be clearly presented, while the information is provided in an easily accessible format, such as video blogs. Suncare has conducted an action research project which suggests that participants will respond most effectively to this learning style when a video is a maximum of six minutes.

**Question**: *How can we encourage carers to participate and complete an education programme?*

**Suncare’s Response**: Carers need to be informed of the benefits of participating in educational programs, including the cost benefit, eg how it will improve life wellness and better access to services.

Peer carers could also provide mentoring throughout the carer’s educational program to encourage them to stay engaged, particularly during times of difficulty, eg fatigue.

**Question**: *How can the future Integrated Care Support Service help carers to be aware of, and access education which may be relevant to them outside of these carer focussed supports?*

**Suncare’s Response**: The Integrated Carer Support Service Intake (Customer Service) would need to maintain a log of all current education programs available to carers, including those provided outside of carer support funding. These could be promoted online through reciprocal service organisations, social media, as well as targeted promotions directly to carers, and through other community organisations, including healthcare and educational providers.

**Peer Support**

**Question**: *What are some of the tools or supports which could assist in delivering peer support to a broader base of carers in a cost effective manner?*

**Suncare’s Response**: Peer support proves to be an effective and reliable source of help for many carers, who are able to connect in a unique way to share similar experiences and learn from each other. Examples of Suncare’s peer support programs include:

Suncare facilitates an effective peer support service to people who identify as Aboriginal and Torres Strait Islander through its Nandjimadji art program.  During the past 10 years this program has demonstrated positive outcomes for carers, particularly those caring for people with mental illness and disability, by connecting with their peers.

The program’s success is its focus on painting, rather than a meeting to engage in peer support, and the group recently initiated a project to sell members’ artwork. Other key aspects include:

* There is no cost for participants to attend.
* Suncare supplies art materials and, in some instances, transport to and from the venue.

Suncare also runs peer support programs with young carers such as retreats, as well as fun and educational activities. As young carers require time to develop their peers’ trust without feeling vulnerable, ongoing, smaller peer groups are essential to build bonds and connections for this group. Young Carers also have their own Facebook page which creates online peer support and mentoring in a socially acceptable way.

Monthly Dementia Cafes have been set up across Suncare’s regions. Initially, a facilitator establishes the group, and as it matures carer participants take ownership of the group. It is a cost effective model, as the carers pay for their own coffee and food. The group provides carers and recipients access to a social activity while feeling safe and supported among their peers. These groups link in with other community organisations such as Dementia Advisory Service whose representatives attend a meeting and provide information.

My Time is another example of a cost effective peer support group run by carers. Volunteers from community organisations share what support and services are available to carers.

**Question**: *How can a peer support model be designed which encourage carers to participate and remain engaged?*

**Suncare’s Response:**

Based on the learnings of Suncare’s Nandjimadji Art Group, Young Carers and Dementia Cafes, peer support needs to be:

* Culturally relevant
* Safe
* Affordable
* Engaging
* Valued by the broader community (non-stigmatising)
* Facilitated – designated leadership and administration

Continue to engage people who are no longer in a caring role to become mentors; they often feel there is a large gap in their life as they struggle to find their identity outside the caring role. Match mentors with carers who have similar experiences so the information, support and advice is relevant to the individual.

Suncare receives enquiries through the Commonwealth Respite and Careline Centre from people who are no longer in a caring role wanting to be part of a carer group so they can share their experiences and knowledge. They now have time to do this and often want to help current carers who are going through a similar situation.

**Question**: *Should peer support be a service able to be accessed without pre-conditions or structure processes?*

**Suncare’s Response**:  Any formal peer support service needs to identify its terms of reference (or service description) and rules of engagement and participation. Ideally, all carers who access a formal peer support service would be registered in a centralised database.

Flexibility is required when facilitating peer support, with carers running their own peer groups to ensure their sustainability, eg dementia café groups.

The peer support group must also be locally relevant rather than prescribed, eg frail aged or younger parents with children with a disability.

**Needs Identification and Planning**

**Question**: *To what extent do you think goal based planning should be used at the assessment stage of the process?*

**Suncare’s Response**: Goal based planning is a logical aspect of assessment. Suncare has successfully implemented the My Aged Care Regional Assessment Service across six regions in Queensland.  Although the in-home assessments are focused on the care recipient (people aged of 65+ years, or 50+ years for Aboriginal or Torres Strait Islanders), Home Support Assessors experience a smooth transition from the identification of client needs through to goal based planning – resulting in a client Support Plan.

***Recommendation 1:* A comprehensive and integrated assessment service.**

Suncare recommends that carer assessment services be added to the scope of the Regional Assessment Services where goal based planning (Support Plan) is already a standard practice. The plan is uploaded to the central client record on the Integrated Carer Gateway and is available to carer support providers chosen by the carer.

**Question**: *Would a goal based planning approach be worthwhile?*

**Suncare’s Response**:  Goal based planning would identify the intended, measurable outcomes of the Integrated Carer Support Service.  It would also guide the carer to specific services which meet their needs, rather than moving towards meeting the care recipient’s needs (Suncare acknowledges that these are not always mutually exclusive).

Goal based planning depends on the carer’s situation. Commonwealth Respite and Carelink Centres use service delivery plans for all carers, including those accessing short term emergency respite. Each respite episode provides a goal to alleviate the carer’s current stress and needs. However, for carers accessing short term emergency respite, longer term goal setting is not appropriate, eg a carer requesting respite for a hospital stay. Reviews with these carers would lead to future planning and discussions around formal and informal supports.

**Question**:*To what extent should self-assessment form part of the future model?*

**Suncare’s Response**: Carers should be involved in the design and formulation of their own service requirements.  However, relying on self-assessment only is unlikely to be an effective tool for determining the carer’s need, as they are likely to overlook their own needs and focus on the care recipient’s needs. Self-assessment would need to be supplemented with a professional assessment service. If online registration and self-service option is available, the carer could complete a self-assessment, with a follow up from an assessor.

**A Multicomponent Intervention**

**Question***: How can we ensure these supports are allocated to those carers who will benefit the most from them?  What should be the criteria by which this is determined?*

**Suncare’s Response:**Suncare has been operating Commonwealth Respite and Carelink Centres in the Brisbane North and Central Queensland regions since 2003. Staff have frequently discussed the prioritisation of a carer’s need and the allocation of funds.  As there are no specific guidelines or criteria many of these decisions have been based on day-to-day consumer demand.  Further discussion is needed around the definition and design of a national carer needs assessment tool.

Suncare does not believe there can be an infallible, predictive tool to determine if a carer will need a multicomponent intervention to enable them to sustain their caring role, avoid a crisis and improve their overall wellbeing; all carers are deemed to be at risk in this regard.  In the day-to-day management of limited resources, the priority of need is based on:

1. A limit on the resources available
2. The level of carer stress (as measured on K10)
3. Capacity to pay – self fund
4. Other emergency criteria – unplanned hospitalisation, accident and ill-health
5. The carer’s history of support
6. Access to other informal support network (or degree of social isolation)

Suncare uses a priority of access tool to assess carer needs to ensure staff consistently provide support to those most in need. Carers are assigned a rating to ensure limited resources are distributed equitably and to those most in need. This tool is based on the Commonwealth Respite and Carelink Centre guidelines.

***Recommendation* *2*: National priority assessment tool**

The priority tool used by Suncare provides a consistent approach across all the organisation’s Commonwealth Respite and Carelink Centres. A standardised tool for determining the priority of need for carers seeking support services is warranted to ensure consistency.

**Financial Support**

**Question**: *How can we help carers to use these funds appropriately without large administrative burdens on cares or providers who may be assisting them?*

**Suncare’s Response:**Suncare has been operating a consumer directed respite care service since 2010.  It also managers several consumer directed aged care packages, and disability packages under the Queensland Your Life Your Choice program.

Suncare believes the management of a client funding package can be a burden (time-wise and mental stress) for some carers, therefore a professional administration service can provide tremendous support.  As with other reforms in the aged care and disability sectors where a market driven approach is being introduced, Suncare believes that market forces should ensure that management fees are kept at a minimum as package administration services compete for customers based on price.

**Carer Mentoring**

**Question**: *When would a coaching programme be most effective for a carer?*

**Suncare’s Response:**Given that carers do not like the term ‘coaching’ it suggests that a coaching program is not appropriate for them.  however, one-to-one support or mentoring is likely to be more beneficial, particularly in a preventative approach, if introduced to a carer when they first take the carer role.

***Recommendation 3*: Carer coaching be an integral component of package administration.**  Suncare recommends that the coaching component of an Integrated Carer Support Service be included in the role description for a package manager/ administrator.  Suncare believes people who deliver this style of support to carers must be trained and qualified.  Competency skills would include: active listening, information giving, goal-based (solution focused) planning, and motivational interviewing.

**Question**: *Should coaching be a mandatory part of the service? Or should mentors be able to determine whether the carers have the capacity to forgo coaching until another time?*

**Suncare’s Response**: Suncare believes that coaching should not be a mandatory part of the service.  A carer may not be comfortable being told they must have a coach.

Quality information presented by a trusted person, with the right amount of encouragement, could help carers, particularly new carers, to self-select if they think they would benefit from such a service, which should not be cost-prohibitive.  Personal testimonies from other carers could also be of benefit.

**Respite Support Service**

**Question:***Will moving to more of a consumer directed model, where funding is attributed to an individual carer result in unintended effects?  What might these be and how can they be mitigated?*

**Suncare’s Response:**The funding model for respite services needs to be multifaceted, both consumer directed and block funding.  Only if funding was specifically available for respite could there be assurance that it would be spent on respite services to provide support for the carer, not the care recipient.

Block funding for emergency respite and education opportunities is essential to ensure it is available for activities which may not be deemed a priority for a carer in short term planning.  While some carers may have made provisions and planned for unexpected emergencies, others may only manage their funding on a day-to-day need basis rather than forward planning.

In its management of the National Respite Care Program and other Respite brokerage funding, Suncare regularly has conversations with carers about the appropriate use of the funding, in particular, financing a holiday for the carer. People frequently call the Commonwealth Respite and Carelink Centre to enquire if the funding would cover travel, accommodation and other incidental expenses, including a cruise holiday, while they take a break from their caring responsibilities.  It is possible that such a request is valid, however there is a general concern that use of funds in this way is neither efficient nor has long-term strategic benefit.

Suncare’s experience with the Commonwealth Respite and Carelink Centres has also witnessed the few unscrupulous service providers directly targeting vulnerable people to promote their services and charging high prices. These providers persuaded carers that they needed their services for extended periods while the cost of their services were not competitive.

Inappropriate and/or inefficient use of carer respite funding would be best mitigated if each carer worked in partnership with a package manager/administrator to set their individual goals (both long and short term), co-design their service plan, and budget their funding accordingly.

**Counselling**

**Question:** *What other counselling programmes and techniques would be beneficial in reducing carer burden?  Could these be delivered to a broader group of carers through telephone on online channels?*

**Suncare’s Response:**Although there is a large evidence base for the effectiveness of Cognitive Behaviour Therapy, there are several counselling therapies available which can be of benefit to carers, for example Solution Oriented (Focused) Therapy, Narrative Therapy, Emotion Focused Brief Therapy, Relationship Counselling, and Motivational Interviewing. The most effective delivery of these therapies would be face-to-face, but could also be delivered via telephone or online video, similar to the telehealth model.