Government of South Australia
Health
Southern Adelaide Local Health Networ

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7th June, 2024

Attention: Mr Ian Yates
Acting Inspector-General of Aged Care
Office of the Inspector-General of Aged Care
PO Box 350
Woden ACT 2606

Dear Mr Yates,

Re: Review – Administration of My Aged Care

In response to the above, Southern Adelaide Palliative Service (SAPS) Psychosocial team wish to share experiences of interactions and outcomes with My Aged Care (MAC) for submission and consideration, with the intention to inform the review process and support a greater understanding of palliative care patient's consumer experiences.

SAPS is a specialist palliative care service that provides a multi-disciplinary response to support patients diagnosed with a life-limiting illness through the delivery of specialist nursing/medical services to support symptom management, end of life planning and end of life care, including navigating through government systems such as MAC to access appropriate in-home support services. SAPS is not an aged care service provider and does not provide MAC services.

As SAPS Social Workers and Caregiver Network Facilitator, it is our role to assess and support palliative patients psychosocial needs, with this often involving requests for in-home support services to assist with Activities of Daily Living (ADLs) or, when an individual's physical or cognitive functioning capacity declines and/or care needs become too high to be managed at home, requests for support to source a Respite or Permanent Placement within a Residential Aged Care Facility (RACF). These experiences highlight how the MAC system is not responsive in meeting the needs of palliative care patients, who often experience rapid declines that require immediate, proactive responses to ensure their care needs are met safely, efficiently, and effectively and in doing so additionally reduce carer stress and burnout.

In our role we are often speaking with people who are in the throes of managing one of the most challenging of lived life experiences - being diagnosed with, or having a loved one diagnosed with, a life-limiting illness. They are individuals who are under added stressors, many of whom are ageing and who find navigating through large government agencies, such as MAC, to be overwhelming and confusing at the best of times and who are simply looking for supports in a timely manner and/or in times of crisis.

It is often our experience that individuals advise us that they have contacted MAC and registered for an Aged Care Assessment Team (ACAT) assessment however when following up on approvals we are informed by MAC that the individual has been scheduled for and/or undergone a Regional Assessment Service (RAS) assessment only and therefore do not have the appropriate approvals and referral codes in place to support the sourcing of a RACF placement in a timely manner.

It has been our experience, when contacting MAC to request a Support Plan Review (SPR) for the specific purpose of requesting an ACAT to obtain approvals for a RACF Placement (either for Respite or Permanent), that MAC staff members report they are required to submit a referral for a SPR to the RAS assessment team before any further assessments can be undertaken.

These experiences are long-standing. As a team we have previously raised our concerns in June 2022, writing to the Australian Government Department of Health and Aged Care, Health Engagement and Aged Care – SA, Service Delivery Division, Ageing and Aged Care Group to advocate for changes to the system, including the ACAT RACF assessment processes. In response to this, we were informed that:

> *'In June 2021, the Department implemented a change relating to SPRs, which directs urgent referrals by health professionals or service providers, through to a comprehensive assessment where the client's situation meets certain criteria. This change bypasses the need for an SPR and addresses feedback received from the assessment workforce and health professionals which at the time indicated delays in SPRs were likely to cause long delays in the client receiving a comprehensive assessment (in some cases putting the client at risk). The direct comprehensive assessment referral only relates to an existing client who is needing Permanent Residential Care and/or Residential Respite Care'* and further that reforms to the Aged Care system were imminent.

Our experience has been that MAC workers appear unaware of the SPR change mentioned and further that we are still awaiting reforms to the Aged Care system, indeed reforms that consider and include the changing needs of palliative care patients.

As a team, we now proactively contact the RAS assessment service directly to advocate on behalf of the patient for the RAS to submit a referral directly to ACAT. This reduces the burden on patients and carers by eliminating the need for them to go through another unnecessary RAS assessment only then to be referred onto ACAT for yet another assessment in order to be given RACF approvals. This action has worked on some but not all occasions and thus subjected the patient to yet another assessment.

Key issues for palliative care patients (some of these are not specific to palliative care, but have greater impact on palliative care patients):

1. Responsiveness / Timeliness – Assessment, service provision and availability

- Time is limited for palliative care patients, they often experience a rapid decline in physical/cognitive functioning and may require an urgent placement within a RACF however do not have the appropriate ACAT approvals in place i.e., Respite or Permanent codes.
- The current wait time for an ACAT assessments is approximately 2-3 months.
- When contacting MAC the responses a team member receives can vary depending on the individual MAC worker responding to the enquiry i.e., one team member may be informed that MAC can submit a referral for service directly via the MAC portal for supports while another team member will be informed that it is not possible to submit a direct referral unless the patient is with the worker at the time of the call, even though the worker has the verbal consent of the patient to contact MAC on their behalf.
- When directed by MAC to the MAC website 'Find a Provider' TAB and encouraged to search for a provider within an area, with availability, a list of providers is displayed however when contacting a named provider, the provider reports they are 'at capacity' and 'the portal is closed' for new referrals to the service. Finding a provider with capacity is a time-consuming task and often without a successful outcome for either the health professional or the family.
- HCP providers may accept and register individuals without really understanding their needs or having the services in place to meet their needs i.e., having an Enrolled Nurse or Registered Nurse employed within their service especially for palliative patients.
- There are cases where patients have died before the HCP is assigned, even when assessed as a high priority, dying without appropriate support services in place.

- In worse case scenarios, we have submitted requests for an ACAT assessment with an *urgent* priority request however, sadly the patient has died before the ACAT assessment has been undertaken or a RACF placement sourced.
- There are also instances where the patient who is needing an increase in in-home supports has presented or re-presented to hospital as their care needs can no longer be managed at home. This scenario adds to the pressures already being experienced by emergency services, including the Ambulance service and acute health care/hospital setting, and is not the most appropriate environment to meet the needs of the patient, especially our palliative patients.

2. Appropriate process – getting the right assessment first time (RAS vs ACAT) and right approvals.

- Palliative patients who undergo a RAS assessment when needing RACF approval codes are put through an unnecessary process, with probing questions only to have to repeat the assessment process with an ACAT to obtain the appropriate approvals to enter a RACF, further delaying access to much needed supports. This assessment process can take weeks when a RACF bed is needed quickly due to the patients decline or increased carer stress.
- The assessment process is exacerbated, with time wasted for patients when allied health professionals, such as members of the SAPS psychosocial team in the case of SAPS palliative patients, have undertaken an assessment of the patients' needs and determined that they require a HCP or admission into a RACF.
- There are instances where palliative patients are assessed by the ACAT assessor as being a Medium or Low priority for assignment of a HCP, rather than High.
- Individuals believe that they have had, or are waiting to have, an ACAT assessment only to learn that the assessment is to be completed by a RAS assessor who does not have the authority to issue approval codes for RACF Respite or Permanent placements or a Home Care Package (HCP).
- The patient is assessed by an ACAT assessor and approved for a HCP however must then wait for the HCP to be assigned.
- Patients who have been assessed by ACAT and approved for a HCP, and do not want to enter a RACF, are unable to access appropriate support services at home through the Commonwealth Home Support Program (CHSP) in a timely manner, if at all, as CHSP providers often do not have capacity to pick up these referrals so have no choice but to wait many months for the home care package to be assigned.
- SAPS psychosocial team members may request an urgent ACAT however the patient bounces into hospital. ACAT then contact the patient and/or learns that the patient is in hospital and *cancels* the ACAT Assessment because the patient is now an in-patient and insists that the patient is re-referred through the hospital ACAT process or post-hospital discharge. This scenario happens often, is frustrating for the patients and families and appears to be such a waste of time and resources and indeed leaves the patient without the needed supports in a timely manner.
- A hospital ACAT will be undertaken if the patient is seeking to be discharged from hospital directly to a RACF into a Permanent Bed. If a patient is only seeking a period of Respite, the ACAT assessment request can be denied.
- As a service, we are aware of only one RACF that will accept a patient *without* an ACAT and/or approval codes for Respite or Permanent placement. This facility has stated that other RACF's are also able to take in individuals needing a bed and then apply for an ACAT assessment retrospectively however choose not to do so, reportedly due to the increased workload this action would require.

Recommendations

In our roles, we have had many conversations with patients regarding aged care placements, there are very few who wholeheartedly accept the need to transition into an RACF, with the preference to remain at home however the reality is that their care needs are too high to be managed within the home environment.

We propose:

- That a specific MAC palliative care patient pathway be created to prioritise palliative patient needs, fast-track ACAT assessments and streamline appropriate in-home or RACF service delivery.

- Individuals diagnosed with a life-limiting illness and referred to palliative services, be automatically provided with ACAT RACF approval codes for Respite or Permanent Placements as an interim measure while awaiting an urgent ACAT assessment. Based upon conversations had, we anticipate these approval codes would not be exploited or abused, as very few individuals want to go into RACF however concede that they must out of necessity due to functional decline and/or limited in-home support services available to meet their changing needs.

On a positive note, within the last 6 months we have noticed a marked improvement in MAC telephone enquiry wait times, where previously we had regularly been on hold for 30-45 minutes waiting for information on relevant RAS or ACAT approvals, calls are now answered within a much shorter timeframe, often within 5 minutes, which has been a welcomed improvement.

To further support the review process, please find attached a separate document detailing specific case examples relating to patients experiences of the MAC system and service delivery for your further information, perusal, and consideration.

It is our hope that the review currently being undertaken by yourself will acknowledge the unique experiences of palliative patients, which differ from that of the retired or aged, and seek to address and make changes to Aged Care services that ensures an equitable and timely distribution of support services and service delivery to appropriately support palliative patients and their changing needs with responsiveness, flexibility, compassion, understanding and action.

Should you have any queries in relation to the above or would like to discuss the submission further, we would welcome the opportunity.

Yours sincerely,

[redacted]

Assoc Prof Dr Tim To Head of Unit SAPS	Justine Hatton Social Worker SAPS Community North	Jacqui Mortimer Caregiver Network Facilitator SAPS Community North/ South	Isingyah Temple Social Worker SAPS Community South	Zoe Hoy Social Worker SAPS Community South

Anonymised MAC case examples – SAPS patients

Initials	Age	Scenario
DH	80	01.09.2022 – ACAT assessment took place. Approved for a level 3 Home Care Package with a 3-6 month waiting period. 23.10.2022 – DH died before the home care package was assigned.
D'OM	89	19.09.2022 SAPS contacted MAC for the purpose of escalating an ACAT assessment. SAPS was advised that as the referral was still open with the RAS team, MAC could not put it through to ACAT but had to go back to the RAS assessment team again. Within a week of this phone call, the patient presented to hospital and ending up being placed into an emergency respite placement.
BC	65	27.09.2022 - SAPS contacted MAC to find out why there was a delay in BC having an ACAT assessment. BC needed RACF placement. MAC advised there is no request for an ACAT Assessment. A Support Plan Review (SPR) was requested for BC on 1/9/22. This was sent to the original RAS Assessment team, ACN. She advised that the current approvals are: • nursing • personal care • social support individual • meals • OT • goods and equipment SAPS contacted Access Care Network – the assessment has been allocated to an assessor today (27.09.2022) who was due to arrange a home visit to complete another RAS assessment. SAPS advocated for a referral to be put through for an ACAT urgently as BC needed RACF. This was done. BC died on the 03.10.2022 before her ACAT assessment took place.
PA	76	The MAC referral for assessment was rejected while PA was an inpatient in hospital. The referrer was not notified so no referral for Assessment was in place when patient was discharged home. 29.03.2022 SAPS contacted MAC and were informed PA did not have an ACAT assessment, only a RAS assessment which did not meet her needs. PA died on 13.04.2022 so no time for an ACAT assessment to be completed.
PT	86	SAPS contacted MAC in April 2022 requesting a review of PT's Support Plan/ACAT Assessment. The referral request was accepted on the 19.05.2022. SAPS spoke with PT on the 23.08.2022, PT reported she was still awaiting an ACAT assessment.
CB	73	MND SA requested an URGENT review on the 24.02.2022 for in-home services. SAPS called MAC on the 01.03.2022 and was informed the referral had been given to a RAS Assessor and not an ACAT assessor. The delay meant that the patient did not receive the level of care and support needed in a timely manner.

Initials	Age	Scenario
WS	80	08.07.2022 - WS's wife received a telephone call from provider ACH to say there was a 2-3 month for a Home Care Package. WS had died at home on the 06.07.2022
DI	96	14.06.2022 – SAPS contacted Southern Adelaide ACAT, requesting urgent review for DI. They advised they had a cancellation for the following day and would contact primary contact for DI to arrange an appointment. 08.07.2022 – SAPS contacted MAC to advised DI had deceased on 02.07.2022. SAPS queried if ACAT assessment had been completed prior to death. MAC advised Referral for ACAT had been accepted however assessment had not commenced.
SK	69	Self-referral made to MAC on 27.02.2023. SK did not hear anything back. On 01.05.2023, SAPS contacted MAC to be advised that the assessment had been allocated to ACN following previous referral. MAC allowed another referral to be made on 01.05.2023. An assessment was undertaken reasonably quickly however SK was not aware of the outcome. 17.08.2023 – SAPS contacted MAC – an ACAT assessment is due (has been waiting since May 2023.) They advised of CHSP codes that had been allocated to SK at the time of RAS assessment. 08.08.2023 – ACAT assessment completed. SK assessed for Level 3 HCP with high priority for allocation. October 2023 – SK assigned a home care package. However, due to the cost the package to Sylvia it was cheaper for her to continue receiving supports via CHSP.
IK	98	Referred to SAPs via GP on 16.06.2023. Request from daughter to find respite for IK on 24.07.2023. Daughter was of the understanding that he had an ACAT assessment. Upon calling MAC, SAPS was informed that the only assessment IK had was a RAS assessment on 27.06.2023 with Access Care Network. The only referral codes given were nursing and transport. A referral had not been forwarded to ACAT even though the original referral to MAC was for an ACAT assessment. ACAT was booked for 16.08.2023 – 2 months after the initial request and the family was requesting respite in RACF due to carer stress ++. ACAT was completed on 07.08.2023. Approvals given for respite, permanent care and HCP Level 4. Respite booked for 13.09.2023 in Vita. IK stayed in the RACF until his death on 21.11.2023
RW	91	26.09.23 - SAPS contacted MAC for a high priority request for an ACAT due to the need for residential respite. 07.11.23 SAPS followed up request for ACAT request – No ACAT referral had been made to ACAT they could not answer as to what had happened to the referral made to MAC by SAPS on 26.09.2023. Phone call to RAS assessor -APM they report they had only received the referral from MAC on 31.10.2024 (Complaint Reference 2-151146266657) 19.11.23 RAS assessment took place on and a referral to ACAT made on this day so further delaying the initial ACAT request that was made 26.09.2023.

Initials	Age	Scenario
JM	84	JM was discharged home from hospital on 01.09.2023, his condition had deteriorated significantly and he was unable to converse or speak on the phone. He was not registered with MAC and his wife was not able to speak with MAC and had to provide medical evidence that JM was unable to provide consent for his wife to speak on his behalf. Had to get a stat dec completed in order to get an appointment for ACAT assessment. Services he was sent home from hospital with were threatening to withdraw unless funding could be swapped over to CHSP or Home Care package funding. ACAT booked for 08.12.2023 – HCP Level 4 approved with HIGH priority. HCP commenced on week beginning 29.01.2024. JM died on 25.02.2024
FB	74	Initial referral for ACAT made in November 2023 but the referral had been closed as they were unable to speak with FB or his representative to make an appointment. Family were not aware of this. New referral to MAC made on 04.01.2024 for an ACAT (Referral number: 2-151845841989) An ACAT was carried out on 05.01.2024. Approval for Level 3 HCP with medium priority. Current wait time 9-12 months. FB died on 23.05.2024.
PJ	65	Referral made to MAC during his last hospital admission in October 23. PJ lives alone and has MND and was struggling to communicate verbally. Follow up with ACAT they had been trying to reach PJ since 09.10.2023. On 02.11.2023 an appointment for ACAT made for 05.12.2023. Patient has NIV and PEG. Home care package Level 3 approved.
TM	53	Referred to Ability First YIPRAC on 22.02.2024 due to Tracey's deterioration and requiring additional supports at home. Tracey had applied for NDIS in December 2023 but by February 2024 still had not received a decision as NDIA required more evidence, so Tracey withdrew her application for NDIS to access MAC supports. 27.02.2024 – Ability First YIPRAC visited Tracey to do their assessment. 05.03.2024 – My Aged Care confirmed that they would accept the referral for Tracey. 06.03.2024 – ACAT assessment completed (very quickly due to a cancellation.) Tracey assessed as eligible for Level 4 HCP and given residential and respite codes. At a home visit on 19.04.2024, Tracey had just been assigned a HCP and had to take this up by 15.05.2024. However, Tracey's condition deteriorated, and she was admitted to Laurel Hospice on 09.05.2024 and died on 15.05.2024 (the day the HCP had to be taken up by.) The MAC process could not keep up with Tracey's deterioration. Although MAC requested the ACAT assessment very quickly, the HCP took too long to be assigned and Tracey died before it could be utilised.

Initials	Age	Scenario
DB	95	DB was referred to SAPS on 31.03.2024 following a presentation to hospital on 11.04.2024. DB's daughter had recently changed providers of her Level 2 HCP and as a result of this all the HCP funds had been frozen for 70 days. As a result of this we were unable to request a review of her HCP to get her package increased to a Level 4 due to her deterioration. Contact to the Dept of Aging was made to see if there was any way of expediting this process as both parties had agreed that there was nothing outstanding to be processed. SAPS advised nothing further could be done to expediate the process.