

Cognitive Decline Partnership Centre Activity 24 Project Team

Submission to the NSW Law Reform Commission Inquiry into the Guardianship Act 1987 – Question Paper 2

Dear Commissioner

Thank you for the opportunity to make a submission to this Inquiry. We write in our capacity as a team of academic researchers, practitioners and consumer representatives involved in a Cognitive Decline Partnership Centre funded research project. This research team includes members with consumer experience in dementia care, and professional expertise in law, medicine, psychology, aged care service provision, and policy development. The project is investigating community and professional views on supported decision-making, as a potential way of facilitating greater involvement in decision-making and advance care planning by people with dementia and their care-partners. In particular, this submission draws from preliminary evidence collected from:

- examination of legislation and case law relating to Guardianship and supported decision-making across three jurisdictions in Australia, and one overseas (WA, NSW, SA, and British Columbia), with particular reference to people with dementia;
- interviews with people living with dementia and their family carers, investigating their experiences with decision-making;
- interviews with aged-care service providers, investigating their established policies and practices with respect to healthcare and lifestyle decision-making among recipients of aged-care services.

Terms of Reference:

Considering the scope of this research project, and the fact that our work is still underway, we limit our submission to the context of people living with dementia, and within the following Terms of Reference:

- The Report of the 2014 ALRC Equality, Capacity and Disability in Commonwealth Laws;
- The UN Convention on the Rights of Persons with Disabilities;
- The demographics of NSW and, in particular, the increase in the ageing population.

Question 5.1: Formal supported decision-making

5.1(1): Should NSW have a formal supported decision-making model?

Yes. Supported decision-making currently occurs on an informal basis, with a number of associated concerns, including lack of role clarity, lack of legal oversight and a tendency to default to substitute decision-making appointments

in response to any disputes over decision-making.¹ We believe that a formal supported decision-making model has an important role in facilitating the ongoing involvement of a person with decision-making impairments in the process of making decisions about their own lives. Establishing a formal supported decision-making model would enable greater clarity as to the role of the supporter/s. It would also grant status and credibility to the supporter role, which will be of assistance in interactions with service providers and/or government agencies. Finally, it will enable transparency, monitoring and review of supported decision-making agreements. This may be particularly important in contexts where a person may be vulnerable to undue influence or abuse. For people living with dementia, the process of cognitive decline, along with expected fluctuations in decision-making capacity, suggests the need for ongoing monitoring and review of supported decision-making agreements. This monitoring and review process should be undertaken with a view to safeguarding the will, preferences and rights of the person with dementia, while balancing other concerns (e.g. encouraging the functioning of the family unit wherever possible).

5.1(2): If there were to be a formal supported decision-making model, how can we ensure there was an appropriate balance between formal and informal arrangements?

Anecdotal feedback from our research tells us that there are currently many informal decision-making arrangements: although the prevalence of these arrangements cannot be accurately quantified. Our view would be that formalised supported decision-making models should be established with the aim of enabling transparency in the supported decision-making process, while not hindering the use of informal approaches where these are working satisfactorily. We are mindful of previous cautions relating to ‘net-widening’, in which well-intentioned efforts to establish formal supported decision-making processes ‘over-reach’ into cohorts of people for whom they are not required, or

¹ JH [2016] WASAT 20, [22]-[34] (for past 2 years supported by son to continue living at home. Due to recent deterioration in condition it, JH no longer able to make reasonable judgments. Guardian appointed due to considerable conflict between JH’s children making informal decision-making arrangements unworkable); RR [2015] WASAT 142, [34]-[35] (spouse acting as informal substituted decision-maker prior to spouse’s death); TLT [2015] NSWCATGD 48, [78]-[79] (due to family conflict, TLT does not have the necessary support to enable her to exercise her decision-making capacity); MG [2015] WASAT 50, [56]-[62], [76] (conflicting medical evidence re. capacity, but due to family conflict informal arrangements were unworkable); BM [2016] WASAT 79, [54], [60] (son unofficially acting as substitute decision-maker prior to application – guardian required due to family conflict); LGM [2016] WASAT 45, [28]-[44], [99] (GP of opinion that LGM has capacity; however, SAT of the opinion that son had effectively been acting as substitute decision-maker. Given son’s history of drug abuse it was not in LGM’s best interests for informal arrangements to continue ([83])); HNI [2016] NSWCATGD 12 (evidence of some specialists that despite her cognitive disability HNI retained capacity to determine where she lives ([18]), but due to conflict between her siblings regarding where she should live a guardian is required ([26]))

introduce restrictive elements into existing informal supported decision-making arrangements that are otherwise satisfactory.²

To ensure an appropriate balance between formal and informal approaches, we would support inclusion of the following components in formal supported decision-making agreements:

- Formal supported decision-making agreements would be optional agreements. Entry into such an agreement might be encouraged by service providers, family members or the person in need of decision-making support, but are not compulsory;
- The supporter (or supporters) would be chosen by the person who is in need of decision-making support;
- The person may revoke the supported decision-making agreement if they choose, and may establish a supported decision-making agreement with another person (or persons)³;
- The person nominated as the supporter could choose to accept or decline the nomination, and this would be established prior to the supported decision-making agreement taking effect;
- Provision should be made for people to establish formal supported decision-making agreements in advance, to be enacted at a time of their choosing, or in situations where they would otherwise be deemed to be incapable of making the decision on their own, without support.

Under the current Guardianship Act legislation, problems arise under the s33A (person responsible) because of misunderstandings of its hierarchical structure (often amongst those within the structure). This can lead to disputes between people involved in the care of a person, and problems can also arise with third parties not knowing who is the official person responsible. In such contexts, it is likely that the promotion of additional 'informal supported decision-making' roles would lead to further confusion and potential for disputes.

A formal model for supported decision-making could go some way to addressing this, by specifying that the supported decision-making arrangement remains valid until such time as a person is deemed unable to make the necessary decision/s, even with the full involvement of their support person. In this situation, the agreement could specify the situations in which the supporter, or some other person might take the role of a 'representative'. The representative's primary role would be to enact the person's known will and preference, with due consideration of the person's other rights (e.g. right to safety). As a last resort, the representative might make decisions for the person, applying a substituted

² Terry Carney, 'Supported Decision-Making for people with cognitive impairments: An Australian perspective?' (2015) 4 *Laws*, 41.

³ The danger of a person making repeated requests to change the supporter, without ever arriving at a decision, might be addressed by a clause in the process of establishing the formal support person. This clause could acknowledge the person's right to change supporters where they judge that it is *necessary*.

judgement approach.⁴ The provisions for overseeing transitions between the supporter and representative role would require transparency and oversight. The current frameworks for enduring guardianship and enduring attorneys might be retooled for this purpose.

5.1(3): If there were not to be a formal supported decision-making model, are there any ways we could better recognise or promote informal supported decision-making arrangements in NSW law?

The following measures would likely assist in promoting informal supported decision-making arrangements, in the absence of a formal supported decision-making model:

- Clarifying the hierarchical structure in s33A of the Guardianship Act;
- Educating health professionals, service providers and the broader community as to the ‘person responsible’ structure, and its hierarchical nature;
- Clearer guidance as to the roles and responsibilities of informal supported decision-making arrangements. This could be through a combination of community education resources, and setting out a set of decision-making principles in law. These principles could operate to encourage (or require) those in the ‘person responsible’ role, to
 - i. consult with the person about the decision, and endeavour to understand the person’s will and preference with respect to the decision, as far as practically possible
 - ii. establish a (rebuttable) presumption that the person’s will and preference are to be respected and enacted by the person responsible, subject to consideration of the person’s other rights and the rights of others (where these are applicable);
- Establishing a body to enable mediation and conflict resolution, prior to any resort to formal Guardianship appointments. This process would be aimed at resolving conflicts and facilitating the continuation of existing informal supported decision-making arrangements, where these are satisfactory. Ideally, this mediation process should also be accessible in cases where there is no intention of seeking formal appointments before the New South Wales Civil and Administrative Tribunal. The most obvious way forward in this area would be to give such mediation powers to the NSW Public Trustee and Guardian. We envisage this could be done as it has been done in South Australia, where the Public Advocate has powers to mediate disputes.⁵ Alternatively it might be

⁴ Research has documented a number of challenges in implementing the substituted judgment approach in practice (e.g. E Vig, J Taylor, H Starks, E Hopley, K Fryer-Edwards, ‘Beyond substituted judgment: How surrogates navigate end-of-life decision-making’ (2006) 54 *Journal of the American Geriatrics Society* 1692). In light of these challenges, it would be recommended to consider public education and resources to support supporters and representatives in their roles. See also section 5.2(3) regarding decision-making principles.

⁵ Advance Care Directives Act 2013 (SA), Part 7 Div 2 and the Consent to Medical Treatment and Palliative Care Act 1995 (SA), Part 3A, Div 2

possible for a less formal mediation function to be established by a non-statutory organisation.

Question 5.2: Key features of a formal supported decision-making model

5.2(1): Should NSW have formal supporters?

Yes. Bearing in mind the considerations expressed above. We believe that a formal mechanism for supported decision-making will enable greater clarity as to the role of the supporter/s, grant status and credibility to the supporter role, and enable transparency, monitoring and review of supported decision-making agreements.

5.2(2): If so, should NSW permit personal or tribunal appointments, or both?

As stated above in 5.1(2), we believe that personal appointments should be allowed, and should not have to come before the Tribunal in order to be recognised. This will enable greater flexibility in the person being able to choose who they want as their supporter. However, it should also be recognised that some people do not have anyone they could/would want to choose. In these cases, the Tribunal should have the jurisdiction to make appointments when this is necessary.

5.2(3): Should NSW have formal co-decision-makers?

No. We believe that having co-decision-makers, alongside supporters (and potentially some sort of representative decision-making) would be overly complicated and counter-productive. As suggested above in 5.1(2) we support a system in which people have the following options:

- i. Use of existing informal supported decision-making arrangements;
- ii. Establishing formal supported decision-making agreements;
- iii. Where appropriate and necessary, Tribunal appointment of a formal supported decision-making arrangement.

Where supported decision-making is not possible (e.g. due to profound impairments which make communication and/or supported decision-making practically impossible), we support a system of 'representative' decision-making, as outlined by the Australian Law Reform Commission (ALRC).⁶ Within such a system a representative could be:

- i. Formally appointed by the person to be represented (to be enacted immediately or in the future);
- ii. If a person cannot appoint their own representative, and is unable or prefers not to engage in supported decision-making, the representative could be assigned through the existing hierarchy for 'persons responsible' in s33A of the Guardianship Act;

⁶ Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws*, 111 (at 4.98).

- iii. As a last resort, the representative may be appointed by the Tribunal.

Representatives should be guided in their decision-making by a set of decision-making principles, which accompany the legislation supporting the decision-maker's appointment.

Question 5.3 Retaining substitute decision-making as an option

5.3(1): If a formal supported decision-making framework was adopted, should substitute decision-making still be available as an option?

Yes. People may still prefer to appoint a representative to make and/or enact decisions on their behalf, in the event that they are incapable of making their own decisions at some stage in the future, even with support. Our initial research is also indicating that there will be significant service provision challenges and cultural changes associated with the introduction of a supported decision-making model. If there is no recourse to an accompanying system of substitute decision-making,⁷ we foresee a number of challenges with the implementation of supported decision-making in the aged-care context. These challenges may create a 'perverse incentive' among aged-care service providers (e.g. to actively avoid involving an older person in decision-making, due to the formalities and time associated with an unwieldy supported decision-making process). This may have the unintended result of further marginalising older people from an active role in important decisions about their lives.

While the momentum in law reform is (rightly, we believe) moving away from substitute decision-making, we have noted that there is still demand for this approach, in prescribed situations and subject to certain principles. It would perhaps be unduly distressing for people living with dementia (or other conditions associated with progressive cognitive decline), for the system of substitute decision-making to be completely removed. This would have the effect of removing any formalised options for people who wish to delegate certain aspects of their decision-making (or future decision-making) to a trusted person, and could lead to anxiety and distress. We note that jurisdictions such as British Columbia, in which supported decision-making has been well established over an extended period of time through 'Representation Agreements' still maintains recourse for the appointment of substitute decision-makers, under specific conditions.

5.3(2): If so, in what situations should substitute decision-making be available?

We support any moves that will reinforce substitute decision-making as something that should be available for a person to choose for her/himself, but otherwise used only where necessary to avoid harm, as a last resort, and subject to independent review. In considering a model similar to that outlined above

⁷ We support the use of the term 'representative' as defined by the Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws*, 111.

(see 5.2(3)), substitute decision-making could be made available in the following limited situations:

- i. Where a person with decision-making capacity voluntarily appoints a representative, delegating current or future decision-making. Such an appointment should be undertaken with knowledge that there are options for informal and formal supported decision-making, as well as the option to grant the representative limited or plenary scope in the decisions in which they might participate;
- ii. Where decisions need to be made,⁸ and a person with impaired decision-making capacity is unable to make these decisions, even with the provision of all support that is practically available;
- iii. Where an existing informal supported decision-making arrangement, or formal supported decision-making agreement is no longer able to function in such a way that the person, with the available support, meets relevant functional thresholds for decision-making capacity.⁹

We believe that the full and proper implementation of such conditions would require substantial further development in the practice of supported decision-making in a diverse range of situations. It may be that future research will develop new techniques that will enable more nuanced or potent forms of decision-making support. Practitioners and researchers will need to develop a sound body of coherent, evidence-based guidelines to inform supported decision-making. This will enable proper interpretation of terms such as ‘all support that is practically available’.

5.3(3): Should the legislation specify what factors the court or tribunal should consider before appointing a substitute decision-maker and, if so, what should those factors be?

This issue is important as it talks to the jurisdiction of courts and tribunals to impose substitute decision-making, presumably against the wishes of the person who might otherwise have appointed a substitute decision-maker themselves

⁸ We suggest that provisions should consider the ‘necessity’ of decisions, in order to avoid the prospect of substitute decision-making being unnecessarily invoked due to an application relating to a frivolous decision (perhaps complex in nature, but of relatively little importance to the person) and hence hindering the exercise of their autonomous decision-making in respect of decisions that are particularly important to them. ‘Necessity’ might be defined differently by service providers, family members and the person to whom the decision relates, and this itself may become a source of conflict. Issues concerning medical emergencies should be seen as a separate issue and governed by the existing provisions in the Guardianship Act.

⁹ We note here the complexity associated with decision-making capacity thresholds at the interface of a supported and substitute decision-making model. If a threshold level of decision-making capacity is required (either individually or with support), a person may meet the threshold in respect of some decisions but not others. In British Columbia, when such a situation is encountered, and the person (or decision-making unit) is deemed to lack the requisite decision-making capacity, this results in an automatic revocation of the Representation Agreement and replacement with a substitute decision-making appointment. While this is in a number of ways a ‘heavy-handed’ response, we surmise that it may have been shaped through pragmatic concerns about the need for constant oversight of Representation Agreements for every decision being made.

had they wanted one. If the conditions to be adhered to for this are easily accessible, this, itself, undermines the robustness of any supported decision-making arrangement or agreement already in place. We would suggest that courts and tribunals consider the following factors:

- i. the will and preferences of the individual;
- ii. the decision-making capacity of the person, in the context of all available supports;
- iii. the necessity of imposing a formal substitute decision-making order, as opposed to other less restrictive means (e.g. a supported decision-making appointment);
- iv. the suitability of the person who is considered for appointment;
- v. the processes for review, and consideration of revoking the substitute decision-making order, in favour of a less restrictive means (e.g. supported decision-making).

Question 6.1: When supporters and co-decision-makers can be appointed

6.1(1) What requirements should be met before a person needing support can appoint a supporter or co-decision-maker?

A presumption of decision-making capacity should be adopted, with respect to a person's capacity to appoint someone to provide them with decision-making support. If this presumption is brought into question, we suggest that in order to appoint someone as part of a formal supported decision-making agreement, the person should be able to evidence an understanding of who their preferred support person is, and a broad understanding of what the supporter may do to help them make decisions. We believe it is also important that the person needing support has some insight into what aspects of decision-making they require support with.

With respect to informal supported decision-making, we acknowledge that this is already commonly occurring. While mindful of concerns about abuse and undue influence among people who require decision-making support, it is unlikely that this will be helped by imposing burdensome requirements on those who intend to establish informal supported decision-making arrangements. We believe that a more effective means of curtailing abuse and undue influence is by increased community education and support for carers and family members, rather than by placing additional conditions on the establishment of supported decision-making arrangements (especially informal ones).

6.1(2): What requirements should be met before a court or tribunal can appoint a support or co-decision-maker?

See above 5.3(3)

Question 6.2: Eligibility Criteria for Supporters and Co-Decision-Makers

6.2: What, if any, eligibility criteria should potential supporters and co-decision-makers be required to meet:

It will be difficult to impose a set of compulsory requirements, however, in determining the suitability of a person (particularly for a formal supported decision-making agreement) the following factors may be relevant:

- i. Existing/previous roles in providing decision-making support (or other forms of support) to the person;
- ii. Extent to which the person requiring decision-making support endorses this person as their preferred supporter (and why);
- iii. Motives of the potential supporter;
- iv. Relationship to the person (including awareness of established relationships that may be hierarchical or otherwise introduce forms of dependency in the supported decision-making relationship);
- v. Skills and characteristics of the potential supporter, including prior history of dishonest or fraudulent behaviour, bankruptcy and/or criminal offences;
- vi. Geographical proximity and availability to the person;
- vii. Cultural and religious compatibility (or sensitivity to relevant cultural and/or religious factors);
- viii. Any evidence of previous abuse or exploitation of people in dependent relationships.

Question 6.3: Characteristics that should exclude potential appointees

6.3: What, if any, characteristics should exclude particular people from being supporters or co-decision-makers

Where there is a professional relationship between the person and the potential supporter, and if there has been a history of domestic violence, elder abuse, undue influence or exploitation, such as a prior history of dishonest or fraudulent behaviour, bankruptcy and/or criminal offences.

Question 6.4: Number of supporters and co-decision-makers

6.4: What limits, if any, should there be on the number of supporters or co-decision-makers that can be appointed?

Without wanting to impose upon the possibilities for supported decision-making arrangements, we suggest that these arrangements can be more pragmatic if built around a model of up to one formal supporter for each decision-making domain (e.g. health & personal care; finances; property; and testamentary decisions). There should be provision for nominating alternative people to act as supporters if the primary supporter is not available. There should also be no reason to limit the number of people that a person and/or their supporter may consult with in making their decision. Particularly with respect to lifestyle decision-making, the nature of the consultation that might be required (for instance in decisions about how to allocate use of consumer-controlled funding packages for disability support) could be particularly broad. This will be most easily overseen if these various consultations come back through the person, and their primary support person, for review and decision.

Question 6.5: Public agencies as supporters or co-decision-makers

6.5(1): What are the advantages and disadvantages of allowing public agencies to be appointed as supporters or co-decision-makers?

While such an appointment may work in some situations, it could be associated with a number of disadvantages. These could include the potential for costs to the individual, difficulties if service demand outweighs supply, and problems associated with lack of continuity if different staff are appointed to the role. The goal, wherever possible, should be to encourage supported decision-making to occur within relationships with familiar people, who understand and know the person well. There could be some potential advantages in some cases, such as if a person had no access to appropriate supporters, and/or in particular situations in which staff from public agencies might have specific skills (e.g. knowledge of health or social service systems enabling advocacy for a certain outcome to other professional service providers). Overall, we feel that this is not the best use of public agency funding. Instead, investing in community education and developing community capacity to provide high-quality supported decision-making would be a more appropriate use of public funds.

6.5(2): In what circumstances should public agencies be able to act as supporters or co-decision-makers?

As suggested above 6.5(1), this may be a last resort if the person had no access to appropriate supporters. We note that, even at present, if a person has no access to trusted people, they cannot make an anticipatory appointment of the Public Guardian prior to losing decision-making capacity.

Question 6.6: Paid workers and organisations as supporters and co-decision-makers

6.6(1) What are the advantages and disadvantages of allowing paid care workers to be appointed as either supporters or co-decision-makers?

As above 6.5(1) there are potential costs to the person, and there may also be professional conflicts of interest introduced if someone who was involved in the care of the person, or as a provider of other professional services, was involved as a supporter. While paid workers may be able to develop particular skills or capacities in the process of supported decision-making, they are unlikely to develop the optimal levels of familiarity and close, trusting relationships with the person, while maintaining professional boundaries. As above 6.5(1) the goal, wherever possible, should be to encourage supported decision-making to occur within relationships with familiar people, who understand and know the person well.

6.6(2) In what circumstances should paid care workers be appointed as supporters or co-decision-makers?

The use of paid care workers as supporters or co-decision-makers introduces potential conflicts of interest or conflicts of duty. We do not support people in

professional relationships with the person being a supporter or co-decision-maker.

6.7 Volunteers as supporters and co-decision-makers

6.7(1) What could be the advantages and disadvantages of appointing community volunteers as supporters?

Volunteers provide many useful services to the community, and make important contributions to resilience in any society. Our initial research has suggested that people with dementia seek support from familiar people, in the context of trusted relationships. While mindful of existing models of community volunteers as supporters, such as that developed by the Victorian Office of the Public Advocate, we would support the role of community volunteers being focused on facilitating the broader processes of community and civic engagement and person-centred care, rather than specifically engaged to provide supported decision-making. Volunteers could, perhaps, also undertake a ‘community visitor’ role (similar to the Council of Official Visitors)¹⁰, hence facilitating informal oversight of the supported decision-making arrangements provided by others.

6.7(2) What could be the advantages and disadvantages of appointing community volunteers as co-decision-makers?

The same concerns as above 6.7(1)

6.7(3) In what circumstances do you think community volunteers should be appointed as supporters or co-decision-makers?

Mindful of the above cautions this might be feasible in situations where there is an existing and sustainable program (which includes adequate training, supervision and support for volunteers); where there is no-one else available to the person; the potential supporter is ‘compatible’ with respect to considerations under 6.2; and where the person does not have the funds to pay for a professional service provider to undertake the role.

6.8 Powers and functions of supporters

6.8(1) What powers and functions should the law specify for formal supporters?

Within a formal supported decision-making agreement, the standard model could be set up to allow the supporter the following powers and functions

- i. Rights of entry to relevant facilities or service provider organisations, to consult with the person and understand their will and preference;

¹⁰ See website <http://www.coov.org>

- ii. Access to relevant information about the person’s situation, to enable them to collect and review information relevant to decisions that the person is being asked to make;¹¹
- iii. Sufficient time with the person, to explain information relevant to the decision, and to support the person to make a decision;
- iv. The role of the support person may be to advocate for the enactment of the decision made by the person, if this is required.

The person who established the supported decision-making agreement should be able to withdraw their consent and revoke the agreement at any time. Revocation should also be within the jurisdiction of the Tribunal, if there are concerns raised about the actions of a support person, or if the person requiring support lacks the capacity to make a decision about whether to continue the supported decision-making agreement. The Tribunal could be encouraged or required to pursue mediation, prior to revoking a supported decision-making agreement.

Project Team:

The full list of investigators on the project is provided below:

Dr Craig Sinclair (University of Western Australia)
Prof. Meera Agar (University of Technology Sydney)
Sue Field (Western Sydney University)
Prof. Susan Kurrle (University of Sydney)
Kathy Williams (Alzheimer’s Australia Consumer Representative)
Assoc. Prof. Meredith Blake (University of Western Australia)
Pia Castelli (University of Western Australia)
Prof. Cameron Stewart (University of Sydney)
Dr Sascha Callaghan (University of Sydney)
Assoc. Prof. Romola Bucks (University of Western Australia)
Assoc. Prof. Josephine Clayton (University of Sydney)
Assoc. Prof. Kirsten Auret (University of Western Australia)
Karla Seaman (Brightwater Care Group)
Pippa Cebis (Brightwater Care Group)
Angelita Martini (Brightwater Care Group)
Kate Gersbach (Brightwater Care Group)
Meredith Gresham (HammondCare)
Rebecca Forbes (HammondCare)
Julie Bajic (HammondCare)

¹¹ Where this access to information raises privacy concerns, this could be managed through evidence of the person’s consent (in the first instance) or, if this is not possible, by the support person providing evidence as to why the requested information is relevant to the decision for which they are providing support, how it will be safely stored to maintain the person’s privacy, and how it will be securely disposed of when no longer needed. Recourse to the Tribunal for oversight of privacy issues associated with release of information should be reserved for more complex situations.

Helen Radoslovich (Helping Hand Aged Care)
Michelle Hogan (Helping Hand Aged Care)

Of this team, the following contributors were available to review and approve this document prior to submission:

Craig Sinclair, Sue Field, Romola Bucks, Meredith Blake, Josephine Clayton, Cameron Stewart, Kirsten Auret, Meera Agar, Sascha Callaghan, Kathy Williams

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