



13th Annual Oncology  
Social Work Australia  
Conference Program

# OSWA National Conference 2018

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The Things  
We Don't Talk About:  
Psychosocial Challenges  
in Oncology Social Work

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November 8th - 10th November

University House  
Australian National  
University  
1 Balmain Cres  
Acton  
CANBERRA



## PROGRAM DAY I - 8 November 2018

TIME	SESSION	LOCATION	SPEAKER
08:30 - 09:00	<b>Registration</b>		
09:00 - 09:30	<b>Welcome to Country and Smoking Ceremony</b>	Great Hall	Dr Matilda House
09:30 - 09:45	<b>Opening the Conference</b>	Great Hall	OSWA President
09:45 - 10:45	<b>Conference Address</b> <b>The things we don't talk about.</b> Words are very powerful!	Great Hall	Dion Devow
10:45 - 11:05	<b>MORNING TEA - GREAT HALL</b>		
11:05 - 12:35	<b>Keynote Speaker</b> <b>Don't Ask/Don't Tell:</b> <b>Compassion, Courage and Values Across the Care Continuum.</b>	Great Hall	Professor Matthew Loscalzo, LCSW
12:35 - 13:30	<b>LUNCH - GREAT HALL</b>		
<b>CONCURRENT SESSIONS IN GREAT HALL AND COMMON ROOM</b>			
13:30 - 15:00	<b>Abstract Presentation – Research</b>	Great Hall	
13:30 - 13:55	<b>Presentation 1</b> Social Work Interventions in Oncology: An Australian Study.	Great Hall	Rosalie Pockett and Kim Hobbs
13:55 - 14:20	<b>Presentation 2</b> Experiences participating in national collaborative data mining research.	Great Hall	Gini Adcock and Ray Araullo
14:20 - 14:45	<b>Presentation 3</b> "It's a bit like the sword of Damocles hanging over your head": Unmet supportive care needs of women with ovarian cancer, their families and friends.	Great Hall	Sue Hegarty, Hayley Russell, Jane Hill, Annemarie Ferguson and Elizabeth Cooch

<b>13:30 - 15:00</b>	<b>Abstract Presentation - AYA</b>	Common Room	
<b>13:30 - 14:00</b>	<b>Presentation 1</b> 'My heart instantly became so empty': The experience of parentally bereaved adolescents and young adults	Common Room	Cassandra Taylor
<b>14:00 - 14:10</b>	<b>Presentation 2</b> Exploring the hospital-based psychosocial supportive care experiences of parents with incurable end-stage cancer who are parenting children (birth to 18 years old): a qualitative study.	Common Room	Vera Steiner
<b>14:10 - 14:30</b>	<b>Presentation 3</b> Supporting my patients who are also parents. What do I say? What's available for them? Introducing CanTeen's new parental services and online community.	Common Room	John Friedsam
<b>14:30 - 14:45</b>	<b>Presentation 4</b> A stepped-care approach to psychosocial support for all adolescents and young adults impacted by cancer: CanTeen's Psychosocial Model.	Common Room	Dr. Pandora Patterson, Mr. John Friedsam, Ms. Sandy Cham and Mr Peter Orchard
<b>14:45 - 15:00</b>	<b>Presentation 5</b> Seeing Patients as Parents: Helping Parents "do" Parenting during Cancer.	Common Room	P. Patterson, J. Friedsam, F. E. J. McDonald, N. Weeks, E. Schiena, S. Wilson, J. Phipps-Nelson and P. Orchard
<b>15:00 - 15:30</b>	<b>AFTERNOON TEA - GREAT HALL</b>		
<b>CONCURRENT SESSIONS IN GREAT HALL AND COMMON ROOM</b>			
<b>15:30 - 16:00</b>	<b>Abstract Presentation</b> Living with Cancer: an explanatory analysis of 100 women living with breast cancer and their families.	Great Hall	Professor Lynette Joubert and Ms. Sue Oldfield
<b>15:30 - 16:00</b>	<b>Abstract Presentation</b> I'm sorry my dog ate your referral: a new "Social Work Encounter".	Common Room	Nick Hobbs
<b>16:00 - 17:00</b>	<b>AGM</b>		
<b>17:00 - 18:00</b>	<b>Welcome Drinks</b>		

## PROGRAM DAY 2 – 9 NOVEMBER 2018

TIME	SESSION	LOCATION	SPEAKER
08:15 - 08:30	<b>Registration</b>		
08:30 - 09:00	<b>Abstract Presentation</b> "Good News is not benign" Exploring the needs of people with brain tumors at the point of diagnosis	Great Hall	Lydia Bras and Justin Gulliver
<b>CONCURRENT SESSIONS IN GREAT HALL AND COMMON ROOM</b>			
09:00 - 10:45	<b>Workshop</b>	Common Room	
09:00 - 10:45	<b>Workshop</b> Understanding Chronic Sorrow: The social work role in promoting a model of compassionate practice for healthcare workers with parents of children with chronic oncological conditions.	Common Room	Katie Lindeberg
09:00 - 10:45	<b>Abstract Presentations</b>	Great Hall	
09:00 - 09:30	<b>Presentation 1</b> Is it blind faith: the acceptance and implementation of international frameworks that do not reflect upon the Australian Context.	Great Hall	Mark Brown, Betsy Sajish, Kim Hobbs and Dr Laura Kirsten
09:30 - 09:50	<b>Presentation 2</b> The 'price' of Diversity and Globalisation: The Less Spoken 'World Family'.	Great Hall	Ray Araullo, Ian Kerridge and Manish Subedi
09:50 - 10:20	<b>Presentation 3</b> Death, Dying and Quality Improvement.	Great Hall	Bianka Eifler and Anastasia Anastasiou
10:20 - 10:45	<b>Presentation 4</b> Supporting Cancer Patients at Kenepuru Medical & Oncology Day Unit: Improving Access to Care.	Great Hall	Justin Gulliver

<b>10:45 - 11:15</b>	<b>MORNING TEA</b>		
<b>11:15 - 11:45</b>	<b>Abstract Presentation</b> Cancer and LGBTIQ	Great Hall	Karen Price
<b>11:45 - 12:45</b>	<b>National Invited Guest Speaker</b> "Facing the Unthinkable/ speaking to the unlanguage"	Great Hall	Elisabeth Shaw
<b>12:45 - 13:45</b>	<b>LUNCH - Poster authors will be available to discuss their posters from 13.00 - 13.30</b>		
<b>13:45 - 14:00</b>	<b>Abstract Presentation</b> Valuing the Continuum of Experience	Great Hall	Melanie Greenhalgh
<b>14:00 - 15:30</b>	<b>Panel Discussion</b> The things we don't talk about ...Secrets	Great Hall	Panelists: Elisabeth Shaw, Melanie Greenhalgh, Dr. Nicole Gorddard, Margo Maloney and Eileen McNally  Facilitator: Professor Matthew Loscalzo
<b>15:30 - 15:45</b>	<b>AFTERNOON TEA</b>		
<b>15:45 - 16:15</b>	<b>International Guest Speaker</b> What medical oncologists depend on social workers to tell them: What are they afraid of?	Great Hall	Joanne Mortimer MD
<b>CONCURRENT SESSIONS IN GREAT HALL AND COMMON ROOM</b>			
<b>16:15 - 17:15</b>	<b>Abstract Presentations</b> <b>Taboos and Personal Experiences</b>	Great Hall	
<b>16:15 - 16:45</b>	<b>Presentation 1</b> Whose voice is loudest?	Great Hall	Lizzie McNulty, Justine Schutz, Kate Nield, Katherine Maughan and Angela Richards
<b>16:45 - 17:00</b>	<b>Presentation 2</b> The G Word: Bridging the Divide – A SW's Journey into the World of Spiritual Care	Great Hall	Karen Rolfe
<b>17:00 - 17:15</b>	<b>Presentation 3</b> Compensation is Not a Dirty Word.	Great Hall	Olga Gountras

<b>16:15 - 17:15</b>	<b>Abstract Presentations Distress Scales</b>	Common Room	
<b>16:15 - 16:45</b>	<b>Presentation 1</b> Hauora/Wellbeing Assessment (taking the plunge to ask the question)	Common Room	Janice Brown
<b>16:45 - 17:15</b>	<b>Presentation 2</b> Rapid Psychosocial Assessment Clinic: Accelerating access to psychosocial services.	Common Room	Betsy Sajish, Mark Brown, Dr Laura Kirsten and Vincent Towell
<b>17:45 - 21:30</b>	<b>Sightseeing to conference dinner</b> Contentious Character Winery, Wamboin.		

## PROGRAM DAY 3 – 10 NOVEMBER 2018

TIME	SESSION	LOCATION	SPEAKER
<b>08:30 - 09:00</b>	<b>Registration</b>		
<b>09:00 - 10:30</b>	<b>Skills Workshop Part 1</b> Helping The Really Difficult Person While Saving Your Own Psyche	Great Hall	Professor Matthew Loscalzo, LCSW
<b>10:30 - 11:00</b>	<b>MORNING TEA</b>		
<b>11:00 - 12:30</b>	<b>Skills Workshop Part 2</b> Helping The Really Difficult Person While Saving Your Own Psyche	Great Hall	Professor Matthew Loscalzo, LCSW
<b>12:30 - 13:00</b>	<b>Conference Close</b>		
<b>13:00</b>	<b>LUNCH</b>		

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## National Keynote Speakers and Panel Members



### Dion Devow

**Managing Director Yerra, Managing Director- Darkies Design, ACT Australian of the Year, ACT NAIDOC Person of the Year.** Dion Devow is a Canberra based business man and the Managing Director of Yerra ([www.yerra.com.au](http://www.yerra.com.au)) and Darkies Designs ([www.darkiesdesigns.com.au](http://www.darkiesdesigns.com.au)). Dion was born and raised in Darwin and is of both Aboriginal and Torres Strait Islander descent and is Traditional Owner for the Palm Island Group of Northern Queensland, (Manbarra) and also has heritage that stems from Darnley Island in the Torres Straits. Dion has a Bachelor of Applied Science in Health Education and has supported Aboriginal and Torres Strait Islander people's access to health, justice, and education for more than 20 years in Canberra ACT.

Dion worked as a Member of the ACT Aboriginal and Torres Strait Islander Education Consultative Group from 2009 to 2014 and for much of that time was the Deputy Chair, and has recently been elected to the ACT Aboriginal and Torres Strait Islander Elected Body ([www.atsieb.com.au](http://www.atsieb.com.au)). Dion uses this 20 years of experience to work as a consultant specialising in community engagement within Health, Education, Justice and is now consulting within the Business sector to assist Aboriginal and Torres Strait Islander people to reach their dreams and aspirations with respect to business.

Dion is recipient of the 2017 ACT Australian of the Year, winner of the 2014 ACT NAIDOC Business of The Year, and the current 2016 ACT NAIDOC Person of The Year, Dion is also the ACT representative for the First Australians Chamber of Commerce and Industry (<http://facci.org.au/>).



### Professor Matthew Loscalzo, LCSW

Matthew J. Loscalzo is the Liliane Elkins Professor in Supportive Care Programs in the Department of Supportive Care Medicine and Professor in Department of Population Sciences. He is also the Executive Director of the Department of Supportive Care Medicine and the Administrative Director of the Sheri & Les Biller Patient and Family Resource Center at the City of Hope-National Medical Center, Duarte California, USA.

Professor Loscalzo has over 37 years experience in caring for cancer patients and their families. He is recognized internationally as a pioneer in the clinical, educational, and research domains of psychosocial aspects of cancer. Professor Loscalzo was the President of the American Psychosocial Oncology Society and the Association of Oncology Social Workers. He is highly recognized and sought after for his strategic mentorship of leaders across disciplines. Professor Loscalzo has focused pain and palliative care, the implementation of problem-based screening programs, gender-based medicine and problem solving therapies. Along with James Zabora, ScD, they created the first prospective universal clinical biopsychosocial screening program in the United States.

Professor Loscalzo has held leadership positions at Memorial Sloan-Kettering Cancer Center, the Johns Hopkins Oncology Center, the Rebecca and John Moores Cancer Center at the University of California at San Diego and is now in his 10 year at City of Hope-National Medical Center. He has created a number of highly integrated interdisciplinary biopsychosocial programs based on a unique staff leadership model.

In 2010, he received the Outstanding Education and Training Award Recipient from the American Psychosocial Oncology Society. In October 2014, Professor Loscalzo was recognized for a lifetime achievement award in clinical care with the Noemi Fisman Award for Lifetime Clinical Excellence from the International Psycho-Oncology Society. In August 2015, he received the Jimmie Holland Lifetime Leadership Award from the American Psychosocial Oncology Society. In 2016 Professor Loscalzo received the Harold Benjamin Innovation Award, Cancer Support Community and in August of 2017, he was the recipient of the Arthur M. Sutherland Lifetime Achievement in the Field of Psycho-Oncology, International Psycho-Oncology Society.

He is the PI on two 5 year NIH R25E training grants (teaching health care professionals how to build supportive care programs and biopsychosocial screening programs) and a site PI for a new third R25E to teach advanced cognitive behavioral skills. He is also on the editorial boards or a reviewer for a number of professional journals and has over 75 publications. His clinical interests are gender-based medicine, strengths-based approaches to psychotherapies, problem-based distress screening and the creation of supportive care programs.

### Elisabeth Shaw CEO Relationships Australia NSW

Elisabeth Shaw is a clinical and counselling psychologist who has spent her career working with couples and families. She is currently CEO of Relationships Australia NSW. Her teaching and publications have focused on areas of clinical practice, such as domestic violence and family safety, sex and intimacy, and best practice in clinical supervision.

Elisabeth is also a senior consultant at The Ethics Centre, and has been past chair of ethics for the Australian Psychological Society and PACFA. Reflective of her fascination of the literatures in moral psychology and moral philosophy, she has written extensively on these themes in couple and family life, as well as contributing to the professional literature with a book on Ethical Maturity in the Helping Professions with co-author Michael Carrol, as well as a number of follow up publications on professional ethics and ethical decision making from a relational perspective.



### Dr. Joanne Mortimer M.D.

Joanne is a vital member of the City of Hope team since 2007, is the Baum Family Professor in Women's Cancers, and vice chair and professor of the Department of Medical Oncology & Therapeutic Research. Joanne received her medical degree from Loyola University and has over three decades of experience in medical oncology. It was her oncology rotation at Loyola that inspired her to focus on battling cancer. She is a member of the Breast Cancer and Women's Cancer Team and many Cancer associations and Boards.



### Melanie Greenhalgh

Melanie Greenhalgh's qualifications and expertise comes from 20+ years in the youth, community and human services industry. Like many of us Mel has also learnt a lot from the 'school of life' as she faced adversity – all of which have helped her develop a personal resilience, grit and empathy for life. With the death of her mother and her sister within 6 months of each other in 2009 life changed for Mel and shook the foundations of her being. Mel had to make a choice - curl up in bed and let it all happen around her or get up and get what her family needed. It is these experiences and more that have created a passion within Mel to share her story and get people talk about death, dying, grief and loss.



### Dr Nicole Gorddard

Dr Nicole Gorddard is a senior staff specialist in medical oncology at The Canberra Hospital and specialises in breast and head and neck oncology. She is the chair of the breast multidisciplinary meeting at The Canberra Hospital and is the medical oncology representative of The Canberra Hospital Drug and Therapeutics Committee. She is actively involved in teaching through the ANU medical school and is also engaged in clinical trials research with The Canberra Hospital medical oncology clinical trials unit.



### Margo Moloney

Margo Moloney has a background in Psychology and Social Work, and is currently working for CanTeen supporting young people affected by cancer.

Her enthusiasm for working in the oncology sector comes from her own brain tumor battle in her early 20's, giving her a unique insight into how cancer can turn a young person's world upside down. Having taken an alternative route of treatment, Margo is an advocate of integrative oncology and of patients feeling empowered through their cancer journey. With this personal experience comes the challenges of navigating self-disclosure, empathy, and professional boundaries whilst providing psychosocial support to young people living with cancer.



### Eileen McNally

Eileen McNally grew up in mental hospitals so her first job was as a nursing assistant in locked psycho-geriatric ward in south London in 1974. It gave her a taste for colourful people in dark places.

During her subsequent career she has met all sorts of people as colleagues and customers. She has worked with criminals wherever they were as well as sick people and their families wherever they were. Eileen has been in kind teams and cruel teams, met people who were disfigured, anguished, wise, desperate, handsome, content, people she liked and people she didn't like.

She thinks of herself as quite modern but tries hard to manage all this by adhering to old-fashioned social work values of unconditional positive regard and, in relationships, respect, imagination, benefit of the doubt and not saying everything.

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## POSTERS

1. Paediatric Oncology Social Work ...A New Model of Care  
Author: Janine Kemp
2. Emotion Coaching For Parents in the Paediatric Cancer Population  
Authors: Ruth Granata, Emma Walkinshaw and Rebecca Summerill
3. Life after Cancer treatment – a peer support group pilot study  
Authors: Andreea Ardeleanu and Elly Law
4. 'All the things we talk about' – Enhance: Epworth's Multidisciplinary Breast Cancer Outpatient Rehabilitation Program  
Author: Liz Alsop
5. The Things that We Don't Talk About.  
Author: Cheryl Butcher

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## Abstracts

### **The Things We Don't Talk About.**

Words are very powerful! The Word ( Bible) says that they can be healing to your bones or that a word fitly spoken is like apples of gold in a setting of silver. So why do we find it so hard sometimes to speak the truth, or to say the things that should be spoken about. There are so many things we don't talk about or say that should be said. We live in a world of extremes, where political correctness can often hinder the learnings of our societies due to cripple peoples conversation and making people so fearful that they are don't ask the questions that need to be asked.

When choosing a name for my Aboriginal and Torres Strait Islander clothing label " Darkies Designs" many people were horrified that I would or could even contemplate using such a word due to its negative use throughout history. However I used this deliberately to negate the historically negative use of the word and to express pride in my skin colour and of my Aboriginal and Torres Strait Islander heritage, and in doing so I invited ALL Indigenous Australians to join me in this celebration.

I also wanted to make the word "DARKIES" a word that wasn't a "bad" or negative word for my MOB and, much to my delight, and although it has taken nearly a decade, the people of Australian, both black and white saw what I was trying to convey, they got the message, and much to my surprise, they started in acknowledge and award me for my vision and for my ability to think outside of the box, to start conversations, and to really express myself as a PROUD Black Man!

*Dion Devow*

### **Don't Ask/Don't Tell: Compassion, Courage and Values Across the Care Continuum.**

This highly interactive presentation will explore and discuss core values and barriers to making deeply meaningful connections with patients, families and colleagues in the context of highly stressful and unrelenting demanding environments. A Staff Leadership Model, along with extremely practical instruments to support compassionate expertise, will be shared.

*Professor Matthew Loscalzo, LCSW*

### **Concurrent Sessions**

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## Adolescents and Young Adults

### **'My heart instantly became so empty': The experience of parentally bereaved adolescents and young adults.**

*Author: Cassandra Taylor Senior Counsellor CanTeen Australia*

In bustling acute hospital wards, or even the hushed hallways of a palliative care unit, the death of a cancer patient carries multiple meanings: a tragedy, a now available bed, logistics, containing grieving families for a time. But once the body leaves the morgue, what happens to the adolescent and young adult children of these patients in the following days, weeks, months and years? Where can oncology social workers direct young people for effective interventions that support their long-term wellbeing. This presentation will draw on current grief theory and interventions including: continuing bonds, the dual process model, meaning reconstruction theory, acceptance and commitment therapy and psychoeducation.

- Understand impact of grief on young people
- Become aware of the research on long term distress of bereaved young people
- Understand effective interventions for this cohort based on contemporary grief theory
- Clarity on implications for practice and referral options

Oncology social workers often work in conditions that do not allow for consideration of psychosocial needs for the surviving family members after a bereavement. This presentation puts their needs front and centre as an imperative for the future generation's mental health.

### **Exploring the hospital-based psychosocial supportive care experiences of parents with incurable end-stage cancer who are parenting children (birth to 18 years old): a qualitative study.**

*Authors: Vera Steiner, Professor Lynette Joubert, Professor Aron Shlonsky, Alison Hocking, The University of Melbourne.*

Parenting is a primary concern for patients who are facing incurable end-stage cancer yet psychosocial supportive care addressing parenting concerns is not routinely provided in the hospital setting. This study will report qualitative findings within the context of a broader mixed-methods research project. The aim of this study was to explore how patients with incurable end-stage cancer (and co-parents) who are parenting children (birth to 18 years old) experience hospital-based psychosocial supportive care – what their supportive care needs are, what interventions were helpful, and their perspectives on how hospital-based psychosocial care could be improved to better meet their parenting support needs.

A purposive sample of 12 patients (and co-parents) accessing treatment at Western Health Sunshine Hospital Victoria participated in semi-structured, in-depth qualitative interviews. Interviews were digitally recorded and transcribed prior to thematic analysis, supported by QSR International NVivo data management software.

Overarching themes that emerged from the analysis include: (1) Multi-dimensional parenting concerns; (2) A proactive approach to parenting; (3) Barriers and enablers to meaningful parenting-focused supportive care practice.

International highlights that parents who have incurable end-stage cancer and are parenting children aged from birth-18 years face unique psychosocial challenges. This study builds on this research by highlighting that parenting-focused psychosocial support in the context of hospital-based care is welcomed but there are topics often left 'unpacked' by both the parents and the health professional – hence, there are 'things we do not talk about' that need sensitive and timely discussion.

### **Supporting my patients who are also parents. What do I say? What's available for them? Introducing CanTeen's new parental services and online community.**

*Author : John Friedsam CanTeen Australia*

One in three adult cancer patients will have a child or children under the age of 26. Talking about cancer to their children is one of the most challenging issues faced by parents. Parents often report being uncertain about what to say for fear of causing further emotional distress to their child, avoiding these 'too hard' discussions, and feeling guilty for not being a 'good parent'. For young people, when a parent has cancer, distress is 3-6 times higher compared to other young people, with young adults generally reporting higher levels of than adolescents. Young people look to their parents to model and demonstrate good communication, emotional regulation and cancer coping.

Since familial data isn't universally captured in minimum data sets, hospital intake forms and cancer registries, the responsibility often rests with front line health professionals to ask about and to explore the familial impact. This presents unique challenges to nurses and other health professionals who have considerable time pressures as well as various degrees of training and experience in parental and/or familial communication and adjustment interventions.

This presentation will explore practical strategies in commencing dialogue with parents around familial impact and communication strategies. Additionally, CanTeen's latest parent and family services and Parent Online Community will be showcased.

### **A stepped-care approach to psychosocial support for all adolescents and young adults impacted cancer: CanTeen's Psychosocial Model.**

*Authors: Dr Pandora Patterson, CanTeen Australia, The University of Sydney, Mr John Friedsam, CanTeen Australia, Ms Sandy Cham, CanTeen Australia, Mr Peter Orchard, CanTeen Australia.*

CanTeen Australia provides psychosocial support to young people (12-25 years) impacted by their own or a family members' cancer diagnosis (Young People Living With Cancer; YPLWC). To address the unmet of needs of YPLWC, the CanTeen Psychosocial Model (CPM) was developed; and includes psychosocial assessment, triage and review. The CPM provides a comprehensive framework for evidence-based psychosocial practice, and was rolled-out nationally July to December 2016.

The CPM psychosocial assessment includes standardised distress and unmet needs measures, semi-structured interview (modified HEADSS assessment), combined with self-identified goals to develop an individualised support plan detailing the stepped care for each client. They are presented at Psychosocial Review Meetings (PRM) attended by a multi-disciplinary psychosocial team. The CPM aids in identification of support needs, treatment planning and periodic review. Services include: individual case management and advocacy, counselling, peer support (programs and recreational activities), access to online support, and external referrals. Underpinning this is a framework of evidence-based practice to reduce isolation, and promote resilience and emotional wellbeing.

The CPM's aim to return YPLWC to a comparable developmental track to those not impacted by cancer is being met. CanTeen currently supports approximately 1900 clients through its CPM, and over 350 PRMs were held January to December 2017. The CPM places young people at the centre of their care, empowering them to develop autonomy and resilience to cope with cancer. Additionally, it provides a strong framework of stepped-care support, ensuring consistency and continuity of care and effective evidence-based intervention for all young people.

While patient support is clearly essential following a cancer diagnosis, AYA family members such as children and siblings of patients, or those who become bereaved are often overlooked. In this presentation we outline an effective model of support for young people who are all too often not spoken about

### **Seeing Patients as Parents: Helping Parents do Parenting during Cancer.**

*Authors: P. Patterson, CanTeen Australia, The University of Sydney, J. Friedsam, CanTeen Australia, F. E. J. McDonald, CanTeen Australia, The University of Sydney, N. Weeks, CanTeen Australia, E. Schiena, Peter MacCallum Cancer Centre, S. Wilson, John Hunter Hospital, J. Phipps-Nelson, Peter MacCallum Cancer Centre, P. Orchard, CanTeen Australia.*

AYA children of cancer patients have significant psychosocial burdens associated with their parent's cancer experience however these young people are often invisible with no clear referral pathways to community-based support. This program addresses these issues along with providing focussed support to patients in their parenting role during cancer treatment.

CanTeen recently began a pilot program of placing a Parent Support Worker in a number of hospitals to provide support to families with cancer where there were adolescent and young adult (AYA) children, and establish referral pathways to community support for these young people.

Being diagnosed with cancer interrupts lives and causes disruption to existing routines. Research shows that one of the greatest concerns for parents with cancer is how to have good conversations with their children about it, and one of the greatest needs for AYA children is information about their parent's cancer along with being able to talk with their parents about it. Additionally these young people are 3-6 times more likely to

have clinically elevated levels of distress compared to their peers and this increases with age. It is known that a strong predictor of positive outcomes in these areas of need is better family functioning.

Three Parent Support Worker positions in 3 hospitals have been established across NSW and VIC to date. Monitoring and evaluation of this novel service is currently underway. Program monitoring results will be discussed and include: volume of referrals/sessions, capacity building of other staff, information given to young people and referrals to community-based support to assist them. Early indications are that the service is integrating into established hospital teams and processes well and adding considerable value with the provision of this focused family support.

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## Research

### **Social Work Interventions in Oncology: An Australian Study.**

*Authors: Rosalie Pockett and Kim Hobbs, Clinical Specialist Social Worker, Westmead Hospital*

Social workers in health settings are often at the forefront of psychosocial support in cancer care; however there have been few Australian studies that have explored the types of social work interventions undertaken with cancer patients. Poorer cancer outcomes are well documented in communities of socio-economic disadvantage, in regional and rural communities and in the Aboriginal and Torres Strait Islander population. This paper will report on the preliminary findings of the third part of a national academic/practitioner collaboration investigating social work interventions in oncology settings in Australia. The study investigated the reasons for referral to social workers, types of interventions undertaken by social workers and documented outcomes of this intervention. The findings will inform future psychosocial intervention with cancer patients and carers in health services and the development of more specific research agenda investigating social work interventions and patient/carer needs.

A clinical data-mining approach was used with social workers reviewing an opportunistic sample of medical records using an audit tool designed for the study. A total of 250 medical records were reviewed across six sites, representing metropolitan, regional, inpatient and day patient centres in three states. Human Research Ethics Committee approval was obtained at each site. Data was entered onto an SPSS database and a cross analysis of elements was undertaken.

Preliminary findings will be presented from the data analysis including demographic data and reasons for referral, cancer information, occasions and types of contact and social work interventions using the Australian national classification system for social work.

The social work oncology literature is almost silent on the psychosocial interventions undertaken by Australian social workers. The findings of this study will demonstrate the scope and importance of their practice. Social work practice is contextualised by the social determinants of health and health inequalities and the findings will provide new knowledge about social work practice with the population with whom they work.

### **Experiences participating in national collaborative data mining research.**

*Authors: Gini Adcock, Oncology Social Worker, Yarra Ranges Health and Ray Araullo, Deputy Head Social Work, Royal North Shore Hospital.*

Research is valued but hospital based social workers do not often participate compared to other health practitioners. While research informs practice and supports funding initiatives, social workers are frequently working with staff shortages in already limited staffing positions where client issues require priority over research activities.

Developing research concepts, designing projects, ethical processes, statistical analysis and literature reviews all require skills that clinical social workers may not have. Research is valued but hospital based social workers do not often participate compared to other health practitioners. While research informs practice and supports funding initiatives, social workers are frequently working with staff shortages in already limited staffing positions where client issues require priority over research activities. Developing research concepts, designing projects, ethical processes, statistical analysis and literature reviews all require skills that clinical social workers may not have. The collaborative nature and data mining design of the project enabled social workers from around Australia to gain skills and participate in a quality research project.

Social workers working alone in stressed and medically oriented teams need support to maintain their professional role. Research identifying their local role/interventions and supporting it with data from other sites may assist with the recognition and appropriate use of social workers.

Methodology: 2 oncology social work researchers from different sites reviewed their research experience of coding their own clinical actions. Case examples were used to demonstrate these experiences.

The social workers had a positive experience, participating in well-supported research, while also identifying the difficulties in coding the complexities of social work practice.

The researchers were able to extend the research project, completing their own related research and presentation as evidenced here!

The researchers learnt more about their social work role and their clients' needs, which may also be used to inform others.

Research in Social work is not talked about. Emotional and spiritual support and quality of life of adult cancer patients/families is not talked about or valued as evidenced by health dollars spent employing social workers.

**"It's a bit like the sword of Damocles hanging over my head". Unmet supportive care needs of women with ovarian cancer, their families and friends.**

*Authors: Sue Hegarty, Support Coordinator, Hayley Russell, Jane Hill, Annemarie Ferguson and Elizabeth Cooch, Ovarian Cancer Australia*

Despite the high burden of disease and aggressive treatment, little is known about the specific psychosocial issues impacting women with ovarian cancer. Ovarian Cancer Australia's 2017 Consumer Survey aimed to identify the major challenges experienced by respondents living with a diagnosis of ovarian cancer and their family and friends and identify needs for information and support.

The survey consisted of an online cross-sectional survey with a mixture of question types including Likert scales, multiple choice and open-ended questions resulting in a mix of quantitative and qualitative data. The survey was distributed to women living with a diagnosis of ovarian cancer, family members and friends who were recruited via electronic direct mail and social media call outs.

323 people affected by ovarian cancer (including women with a diagnosis, their carers, friends and family members) completed the survey. Analysis indicates that women with ovarian cancer and their support networks face numerous challenges. The most challenging aspect identified by respondents with a diagnosis of ovarian cancer was the "fear of cancer recurrence". This was followed by "feeling isolated" and "finding information on treatment options". The least challenging aspect was perceived to be covering the "costs of travelling to attend treatment". 11% of respondents with ovarian cancer felt their friends, family or partners did not understand what respondents were going through as they were experiencing their own grief. For carers and other family/friends the most commonly expressed challenge was effectively supporting their friend or family member through treatment and its side effects (18%).

Little is known about the psychosocial effects of an ovarian cancer diagnosis. This research sheds light on some of unspoken issues at hand including mental health effects, social isolation and sexuality and body image issues. The results will be of interest to a range of health professionals and have implications for psychological interventions and psycho-social support for women with an ovarian cancer diagnosis.

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## **Concurrent session**

### **Living with cancer : an exploratory analysis of 100 women living with breast cancer and their families.**

*Authors: Prof Lynette Joubert, Melbourne School of Health Sciences, University of Melbourne, Ms Sue Oldfield, Manager, Austin Hospital Department of Social Work, Melbourne, Oncology Social Work Team, Austin Hospital Department of Social Work, Melbourne.*

Family members, friends, and caregivers are impacted by the cancer experience yet can be frequently sidelined in the assessment for, and implementation of care plans. Their role is relatively neglected in advocacy and clinical care. Yet their participation in supporting, mobilising and engaging with women with breast cancer remains a central issue for an improved and meaningful experience.

This presentation will report on the outcomes of a study, undertaken in the Department of Social Work at the Austin Hospital, Melbourne, Australia with a consecutive sample of 100 women with breast cancer.

The aim of the study was to define, evaluate and assess the contribution of family and social networks to supporting parenting and improving the patient care experience.

The design used was a prospective cross-sectional study which was implemented utilising an exploratory qualitative methodology with a consecutive sample of 100 women with breast cancer.

The qualitative data was analysed using the Attride and Stirling (2001) systemic model of comparative qualitative analysis.

The results privilege women and family voices in the cancer journey and highlight the range and extent of their experience. Personal adjustment including the emotional response to coping with life issues, emerged as the strongest theme with family adjustment to illness and changes in family relationships a close second. Financial toxicity and coping with social isolation and shifts in social relationships and networks, remained a concern for women grappling with the impact of parenting with cancer. The results have implications for supporting women to parent as they live with a diagnosis of cancer.

We will report on the implication of the results for co-created services.

This exploratory research subject has privileged the voices of women to highlight their preferences for supportive care services. It is focused on engaging with their needs for service and to co-create with them services that are meaningful to them and their families. The research has been implemented within an academic practitioner practice research collaboration and explored a practice issue for social workers in oncology at The Austin in Melbourne.

### **I'm sorry my dog ate your referral: a new "Social Work Encounter"**

*Author: Nick Hobbs, Social Worker, Royal Hobart Hospital.*

How to acknowledge a two month wait by a patient whose referral you had forgotten about? How to keep a track of all those informal referrals on post-it-notes, corridor conversations and scraps of paper pushed under the office door, in greater and greater numbers? Remember the time when you finally got to the referral only to discover that the patient has died? How do we respond to lost referrals, duplications, delays, mismatched expectations and organisational imperatives that undermine work satisfaction and service outcomes?

This presentation outlines an 18 month collaboration between Radiation Therapist Bruce MacDonald, and Social Worker Nick Hobbs, to develop a "Social Work Encounter", an electronic referral system and resources register, within the ARIA Oncology Information System. The "Social Work Encounter" is a novel innovation, available to all Allied Health disciplines with access to the ARIA system, to increase accountability and multidisciplinary communication, reduce duplication and instances of lost referrals.

The "Social Work Encounter" is now utilised across most outpatient oncology clinics at the Royal Hobart Hospital by doctors, nurses, administration staff, radiation therapists and social workers. It has improved clinical handovers within the oncology social work team, eliminated lost referrals and provides an improved pathway for multidisciplinary communication. The "encounter" format is also being duplicated in areas of information administration related to patient registration and coding.

Too often I find myself apologising to clients when I perceive that I am not meeting my own, or a patient's expectation, of timely service provision, due to a delayed or inadequate response. I want to acknowledge the potential rupture but would prefer to not be in this situation at all. I apologise out of respect but what I am apologising for (human error, organisational complexity, under resourcing?) is usually left unsaid.

### **"Good News: It's Not Benign" Exploring the needs of people with brain tumours at the point of diagnosis.**

*Authors: Lydia Bras, Registered Social Worker, Canterbury DHB & Justin Gulliver, Registered Social Worker, Capital & Coast DHB.*

The diagnosis of a brain tumour and recovery following surgery can be a difficult and stressful time. Many patients leave hospital without a confirmed diagnosis, not knowing their prognosis, and not having access to appropriate support. Changes in personality, relationships, function and security contribute to higher psychosocial distress, and the way we share information can affect patients understanding of their health and ability to plan for their futures.

The presenters will share learning from the development of initiatives at Christchurch and Wellington Hospitals to reach patients at the earlier stages of their diagnosis. Using practice and personal examples, they will discuss the role of social work in reducing distress as well as ways in which the initiatives have addressed the inherent institutional barriers to effective adjustment to a brain tumour diagnosis.

Theoretical background: Strengths-based and client-centred practice, empowerment models and Therapeutic social work.

The introduction of additional social work and psychology services at the early part of the diagnostic and treatment pathway improved access and support available, however has been limited by the information that is given to the patient at the point of diagnosis. Issues of power, false hope, and feelings of abandonment have become more evident and have required responses that are more complex. This presentation explores issues of institutional power and its impact on service users. From the reluctance of surgical teams to discuss the potential diagnosis, to the delivery of false hope – the way in which we communicate and talk with our patients is essential to their ability to cope, and, plan for their future. These are the things we do not talk about, and the things that arguable are the most useful to our patients.

### **Concurrent Sessions**

#### **Is it blind faith: the acceptance and implementation of international frameworks that do not reflect upon the Australian context.**

*Authors: Mark Brown, Social Worker, Royal North Shore Hospital, Betsy Sajish, Senior Social Worker, Nepean Cancer Centre, Kim Hobbs, Clinical Specialist Social Worker, Westmead Hospital & Dr Laura Kirsten.*

Australian Social Workers strive to provide a movement for change in the way health and care services are organised around the needs of not only our patients and their families, but also their communities and social networks. We achieve this by utilising existing frameworks in our service delivery. There are numerous examples where care frameworks have demonstrably improved people's care experiences and outcomes, but many of these frameworks are challenged by persistent barriers to successful implementation into Australian clinical practice. Social workers, for many reasons, accept and implement international frameworks (usually developed in a North American context), which can be deficient in their application to the Australian sociocultural context, and this subsequently puts limits on service delivery.

Increasingly health care workers are required to utilise patient reported outcome measures, along with cost and time efficient approaches. It seems timely for Australian social workers to collaborate, and lay the foundation required to design, build and implement effective integrated care frameworks that are adequate to service needs and which supply timely, efficient and patient-centered care to the Australian population.

This presentation will review a popular existing framework and tool promoted internationally for use within cancer care settings. It will explore how this framework and tool was utilised during a cross-sectional pilot study at Nepean Cancer Care Centre. Furthermore it will discuss how the framework and tool were adapted to make them more orientated to the Australian context from a social work perspective. This modification not only improved outcomes for patients but has significant systemic implications for delivering patient-centred care in an Australian oncology context. Implementation of international frameworks that do not reflect upon the Australian context is an aspect that not talked about.

### **The 'price' of Diversity and Globalisation: The Less Spoken 'World Family'.**

*Authors: Ray Araullo; Ian Kerridge; Manish Subedi - Royal North Shore Hospital.*

We describe the case of a 22 year old Nepalese student who became our patient when he presented to our hospital with acute leukaemia – a condition that is incurable without chemotherapy and bone marrow transplant (BMT). He came under our care after being rejected by another major Sydney tertiary hospital on the basis of his 'inadequate' health insurance.

Despite their valid visa status, overseas students (O/S) diagnosed with cancer are not necessarily covered for full cancer treatment and despite the Overseas Student Health Care scheme may still be refused medical treatment.

This is hugely troubling because the majority of O/S come from third world countries, where access to cancer treatment is limited or non-existent. Consequently, O/S are often forced to advocate for themselves for access to potentially lifesaving treatment in Australia – the country that accepted them as students. This is arduous and difficult given the impact of their illness, the complexity of the health system and the barriers resulting from culturally and linguistic difference.

By building trusting and strong relationships with key stakeholders and maintaining constant and transparent communication with them, we were able to negotiate a path for our patient that enabled access to optimal care within the fiscal and political constraints imposed by the Ministry and Local Health District. We are part of a 'world family': Empathy, respect and compassion are key. And while it is undeniable that health systems have borders and not everyone can be treated – when a starving person knocks on your door, you have no option but to feed them.

The argument around the cost of treatment for overseas Medicare ineligible cancer patients often takes precedence over the more human discussion around a person's life and death choices. The patient's voice, overseas or not, ineligible or not, has an equal right to be heard.

### **Death, Dying and Quality Improvement.**

*Authors: Bianka Eijfler and Anastasia Anastasiou, Senior Social Workers, St George Public Hospital*

Clinical social work practice surrounding dying and bereavement in the acute care hospital setting is empathic, reactive, and person-centred. However, it is not universal and gaps in follow-up service delivery and resources may exist when compared to the palliative and international context.

The St George Hospital Bereavement Working Party was formed 18 months ago to review and interpret grief theory, bereavement practices, and consumer needs as a quality improvement project to adopt a palliative care approach to an acute care death. After exploring the departmental practices of grief intervention and comparing it with the literature, a 'bereavement pack' was developed and a model was adopted for memory making on the acute oncology ward.

'Deaths in Australian Hospitals 2014-15' provides a comprehensive analysis of how we live and die. Data suggests that about 50% of Australians die in hospital, and the leading cause of these deaths are neoplasms (31%). These high statistics of acute hospital deaths emphasise the importance of developing high standard, consistent bereavement responses by all psycho-social clinicians involved in an oncology death.

Newer approaches to grief and loss theory have influenced the changes to our practices. Studies suggest that the introduction of legacy or memory making work improves rates of anxiety and depression and increases quality of life. (Chochinov H., Hack T., Hassard T etc al, 2005). Legacy making allows the individual to shift focus away from the cancer to their life and what is meaningful on a personal level. International literature also demonstrates that the provision of generalised follow up following a hospital death is perceived is useful by bereaved families (Walsh, 2008).

Over 100 bereavement packs have been sent out in the past 12 months to family members and next of kin. Consumer feedback is encouraged, and we are collecting data from the packs with a motivation to develop further quality improvement works and prompt potential research. Feedback to date suggests families perceive this ongoing link and the opportunity to create memories on the ward have been beneficial during their grieving process.

The things we don't talk about it' is a key message challenged by the bereavement working party, as it provides a central forum to honour the death work provided by palliative care and social work clinicians. By bringing a psycho-social approach to death in oncology, we are able to discuss, challenge and enhance the service we provide to families on a regular, consistent basis. Dialogue surrounding death through the practical offering of memory making offers an alternative medium of expression, and appropriate follow up after bereavement completes a holistic approach to clinical social work practise in oncology.

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#### **Supporting Cancer Patients at Kenepuru Medical & Oncology Day Unit: Improving Access to Care.**

*Author: Justin Gulliver, Registered Social Worker (Advanced), Capital & Coast DHB*

In a geographically sparse environment like New Zealand, finding ways of providing treatment that is convenient and cost effective is an ongoing battle. A strategic priority for health is to provide care closer to home; however, this can severely hamper access to psychological and social support for those living away from main treatment centres.

This pilot reviewed the needs of a small community of people receiving treatment closer to home who, until the pilot, only had limited access to psychological or social support.

Over a period of three months, an oncology social worker interviewed people starting treatment to establish their social and psychological support needs and assist them to develop a plan that would meet them. Collected data was analysed to gain a clear overview of the level of need and inform recommendations to improve service delivery.

During the pilot, 23 eligible people met with the social worker. All had at least one issue that required social work intervention, and many required longer-term support in the community. The pilot proved that this population have needs that aren't discussed due to their location, the skills and knowledge of staff and the lack of resources available.

In order to provide effective psychological and social support, people need opportunities to discuss their concerns. This presentation examines how we were able to address the problems created by not talking about the needs of the clients and the social-political contributing factors that led to the problem arising.

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## Workshop

### **Understanding Chronic Sorrow Understanding Chronic Sorrow: The social work role in promoting a model of compassionate practice for healthcare workers with parents of children with chronic oncological conditions.**

*Author : Katie Lindeberg, Senior Social Worker Lady Cilento Children's Hospital*

Referencing Simon Olshansky's concept of Chronic Sorrow, this presentation provides comparative overview against traditional grief and clinical depression relevant to clinicians working with parents of children with chronic haematological/oncological conditions in the tertiary paediatric health setting, and the importance of the social work role in advocating for families and educating multidisciplinary clinicians around grief to promote compassionate practice.

Exploring the complexities of grief and the impact on psychological wellbeing at a time of great vulnerability is crucial to promoting positive engagement and collaboration in the medical management of any chronic illness. Within the medical model, parents who may display adverse stress reactions or behaviours are often labelled "depressed" or "difficult", when in many cases we are observing a normal response to a living grief. The grief experience can be compounded by the need to rapidly adjust to new parenting roles. High expectations on parents to cope and "keep up" with medical education and compliance while providing caregiving in a situation that has no predictable end poses additional challenges. Understanding this cyclical grief provides a useful lens with which to view families, challenge judgements and to promote understanding and compassionate practice across disciplines.

By placing a focus on normalising vs pathologizing the grief experience for parents of children with chronic oncological conditions and promoting compassion for clinicians working in this space, social workers are in a unique position to advocate for the individualised needs of the child and parents and promote positive working relationships within the medical system with a view of longevity.

Grounded in grief theories and practice wisdom, this workshop will provide a model of practice and interactive clinical case studies for participants to refine their skills in identifying and support parent carers experiencing this cycle of grief, and to practice with compassion and kindness.

Things we don't talk about – the challenges of normalising grief reactions of carers within the medical model.

Participants will achieve a clear understanding of Chronic Sorrow and a step by step model of practice to employ in their own practice as well as a tool to educate other members of the multidisciplinary team. The goal of the model is to adequately identify and support grief reactions throughout treatment and promote positive psychosocial outcomes for patients and families in the paediatric health setting.

## **Cancer and LGBTI.**

*Author Karen Price, Deputy CEO, ACON.*

ACON delivers a suite of cancer related programs which employs community engagement and peer-led health promotion to target underscreeners and never screeners within the LGBTIQ population.

This presentation will focus on cervical cancer (#AtYourCervix), Breast/ Chest Cancer (#TalkTouchTest) and our smoking cessation programs (#SmokeFreeStillFierce).

For example, risk factors for breast cancer are similar for lesbian, gay, bisexual, transgender, intersex and queer (LGBTIQ) people as they are for the general population, LGBTIQ people experience these risks disproportionately and reportedly interact with prevention and screening programs uniquely. For example lesbian and bisexual women have a 2-3 times higher prevalence of breast cancer risk factors than heterosexual women (Case et al., 2004). And yet, lesbian, bisexual and queer (LBQ) women, compared to heterosexual women, have lower rates of routine screening practices, which can contribute to late diagnosis of breast and chest cancer. These rates are even poorer for trans and gender diverse people (Bazzi et al., 2015).

We will detail the community engagement strategies we employ when working with LGBTIQ people. This includes community events, photoshoots, short film creation and other community capacity building initiatives. Participants will develop an understanding of barriers faced by LGBTIQ people to cancer programs and services.

People from LGBTIQ communities are commonly invisible in mainstream in health promotion and cancer programs. This presentation aims to make visible these invisible populations.

## **Facing the unthinkable, speaking the un-languaged.**

*Author: Elisabeth Shaw CEO RA NSW*

In times of crisis, people need skills they might never have had before; to talk about scary topics, be brave in the face of fear, speak at a level of depth and intimacy that is unfamiliar, tolerate others talking about issues that are deeply uncomfortable. Family members can have varying levels of capacity to discuss what needs to be discussed, and also move through their emotional responses at different paces, meaning that they can be vulnerable to "setting each other off". It is commonly the case that anxiety will rule, and the person with the most fear will control what is possible, and what is not.

Staff need to relate to these complicated dynamics and family "rules" - which may be ill-defined and even unconscious - in roles that include that of "accidental counsellor". This paper will explore the issues that arise for families under stress, and how staff can relate to complex dynamics in ways that still feel fruitful and useful, rather than feeling co-opted into seemingly perverse family arrangements that will impede growth and disadvantage the patient or ethically compromise treatment.

## **Valuing the Continuum of Experience.**

*Author: Melanie Greenhalgh.*

We spend a lot of time consumed with providing continuity of care for patients. There is so much that we don't talk about. Often, it's because patients and their families live in hope that something will change and their health will be restored. It's also because we truly believe that this is an individual journey and therefore it's difficult to cover all the bases. Whilst all of this is true and important, does this mean we should always wait until death and dying is imminent to suddenly talk about the experience? What if we added value to the care experience by having discussions with patients, carers, families, friends and health care providers about the continuum of experience? Let's tell each other how it is, how it might be and all the degrees in between.

Personal Experience from Carer, Patient and Observer. I'd like to provide my personal story and the points at which social worker intervention could have eased the fear and aided us as we prepared for the experience of death and dying with dignity.

As a carer I felt out of control and completely in the dark because I had no idea what was coming, the sounds of it, the smells of it, what it would look like and what the future decisions might be. During that time, I felt alone and scared, I couldn't ask the questions I needed to in her company. My experiences relate to the conference theme about when and how Social Workers must facilitate conversations that others steer away from. When is that appropriate, how do we know if talking about the things we don't talk about are important for our clients rather than meeting our own needs or fostering our prejudices?

### **Panel Discussion: The things we don't talk about .....Secrets**

*Panelists: Elisabeth Shaw, Melanie Greenhalgh, Dr. Nicole Gorddard, Margo Maloney and Eileen McNally*

*Facilitator: Professor Matthew Loscalzo*

### **What medical oncologists depend on social workers to tell them: What are they afraid of? International Guest Speaker - Joanne Mortimer MD**

#### **Concurrent Sessions**

##### **Whose voice is loudest?**

*Authors: Lizzie McNulty, Justine Schutz, Kate Nield, Katherine Maughan, Angela Richards, Social Workers, The Royal Children's Hospital, Melbourne.*

Exploration of child, family and multi-disciplinary voices in quality of life and long-term treatment planning, in a context of increasing curative treatment pathways for complex Oncology patients.

Within paediatric oncology, there have been profound technological advancements in recent years with regards to curative treatment options for children with both malignant and non-malignant conditions. In the context of these advancements and attempts to treat conditions that may have previously been medically "untreatable", adverse reactions and significant complications can often arise in these new treatment processes, resulting in secondary chronic or life-long comorbidities for some children.

In the context of these complications, ethical questions often arise amongst members of the interdisciplinary team with regards to what we are hoping to achieve for a child: to extend that child's life at all costs or to enhance the quality of that child's life?

Content for the presentation was gathered through reflection on common themes in practice through our shared social work team experience, review of relevant research and literature on the topic, as well as key challenges highlighted in de-identified case studies.

This presentation will highlight the complexities of navigating these types of discussions and illuminate the emotional and moral challenges staff face in caring for medically complex children over lengthy periods of time, particularly where staff may have competing mental models within the multidisciplinary team regarding what treatment/s is in the "best interests" of the child. This relates to the theme of the child patient's voice potentially "not being talked about" and how, as clinicians, we can attempt to bring their voice to the forefront in clinical decision-making.

### **The G Word: Bridging the divide - A SW's journey into the world of spiritual care.**

*Author: Karen Rolfe, Pastoral Care Coordinator, St John of God Berwick Hospital.*

Being made redundant after 32 years as a social worker in the health sector, I was encouraged to apply for a job as Pastoral Care Coordinator, managing a small team of practitioners in a private hospital.

I will explore a Social Worker's entry into the world of spiritual care. The word God, faith and spirituality are often held at arm's length in the Social Work profession. Yet, Pastoral/Spiritual care teams are often managed by Social Workers and we are often required to work in partnership, particularly in the field of oncology and palliative care.

I will consider where the common ground is and what the differences are, with a view to how our two professions can best work collaboratively for improved outcomes for patients and their families. The word God, faith and spirituality are often held at arm's length in the Social Work profession.

### **Compensation is Not a Dirty Word.**

*Author: Olga Gountras, National Manager of Social Work Services, Slater and Gordon Lawyers.*

As social workers we are gatekeepers. Whether we openly acknowledge it and do it consciously or unconsciously, we are our clients' gatekeepers. People with a cancer diagnosis can come from all walks of life. Many would be unaware that they may have entitlements to make a legal claim or know how to access appropriate legal information and assistance. Through my hospital experience I found that consideration of legal issues was often not well integrated within the psychosocial assessment framework to meet the needs of patients, particularly those who are vulnerable or marginalised. Through my continued discussions with many social workers over the past nine years, it remains common to hear them admit they too are unaware of their patients' potential entitlements to claim or how legal systems operate. Others are reluctant to suggest to their patients that they seek legal advice or, if they do, will not provide them with appropriate legal options. There appears to continue to be common misconceptions about lawyers and legal processes in Australia. Patients are often left to make sense of the myriad of differences between areas of practice, law firms and lawyers.

Many people are scared to see lawyers because they are afraid of costs and the legal world in general. Many social workers do not understand how legal processes work or law firms operate to explain these to clients and dispel myths and fears; in some cases social workers may share these same fears themselves and continue to perpetuate these myths. Many clients, therefore, will not seek legal advice and are legally and/or financially disadvantaged as a result because they have not obtained their correct and maximum entitlements under the law. The question to be asked is: ethically, what should be the social worker's role in facilitating a patient's access to legal assistance?

### **Hauora/Wellbeing Assessment (taking the plunge to ask the question).**

*Author: Janice Brown, Social Worker Cancer Support Team, Hutt Valley District Health Board Lower Hutt New Zealand.*

Distress can impact on many areas of life and may influence how a cancer patient engages with treatment. Research shows that clinicians are not good at asking about distress. Use of a distress screening tool is well documented and is a requirement for referrals to some Cancer psychosocial support services.

The Cancer Support Team at Hutt Hospital wanted to trial a tool to identify levels of distress and support patients in their treatment process. A pilot using the Hauora/Wellbeing Assessment Tool was conducted to determine whether this would be an appropriate tool in an outpatient setting to start conversations about distress and assist with acceptance of psychosocial support.

Results from the pilot demonstrated the tool was effective in providing a snapshot of levels of distress. There was a positive response from patients. Discussion using the distress scores alongside clinical judgement offered a starting point for social work and psychology input. Enthusiastic 'buy in' by the clinic nurse was an important factor to the success of the pilot.

Work is continuing to extend the use of the tool to other cancer outpatient clinics.

Asking about distress can be one of the 'elephants in the room' for clinicians. Providing a user friendly and non-threatening tool to assist in identifying distress can only be of benefit to patients and clinicians alike.

### **Rapid Psychosocial Assessment Clinic: Accelerating access to psychosocial services**

*Authors: Betsy Sajish, Senior Social Worker, Mark Brown, Dr Laura Kirsten and Vincent Towell, Nepean Cancer Centre.*

Elevated distress and high prevalence of mental disorder in people with cancer has been demonstrated in the literature (Carlson et al, 2012; Mehnert, et al 2014). Despite the prevalence referral is dependent on identification of distress by other health professionals and, of those with high distress levels, only a small number seek and accept support (Baker-Glen, et al, 2011). This study sought to expedite access to psychosocial services in a comprehensive cancer centre in western Sydney, Australia by trialling a Rapid Psychosocial Assessment Clinic (RPAC) that was social work student led.

This cross-sectional study used convenience sampling to recruit people with cancer commencing radiation therapy. Participants were provided with an RPAC appointment immediately following their radiation therapy planning session. In the clinic they completed the distress thermometer, a modified problem checklist and had a brief psychosocial assessment with the social work student.

Fifty people with an average age of 64 years participated. The median score on the Distress thermometer was 3 and the median time spent in the RPAC was 30 minutes (range: 15 to 45 minutes). Main problems identified were nervousness (24%), sadness (16%), and transportation (16%). Overall, 62% of participants required follow-up and referral (usually to allied health).

Limited resource and understaffing of social workers and support staff in provision of psychosocial and supportive care has also contributing to Unmet need of oncology patient.

The issue is ignored when discussing comprehensive care provision.

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## **Workshop**

### **Helping The Really Difficult Person While Saving Your Own Psyche.**

It is essential to admit that some people manifest behaviours that are alienating to most professionals. Love is not enough with this population. When unrecognized and effectively managed: This painful reality has the potential to result in anger, isolation, demoralization and conflict on multiple levels. Trauma by proxy on the family members of social workers is also common. This three hour highly interactive workshop will identify the most disruptive behaviours unique to social work practice but will focus primarily on effective ways to help others while claiming the right for self-protection and wellness.

*Professor Matthew Loscalzo, LCSW*

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## Posters : displayed in Common Room

### **Life after cancer treatment - a peer support group pilot study.**

*Authors: Andreea Ardeleanu, Social Worker and Elly Law, Psychologist, Canberra Region Cancer Centre.*

The Life After Cancer Treatment Group pilot study is a survivorship therapeutic support group targeting people with primary cancer, after completion of treatment. The three main aims of this group are:

1. provide a safe environment for exploring issues characteristic of the survivorship phase and psychosocial education within an Acceptance and Commitment Therapy (ACT) model.
2. provide participants with an opportunity to experience mindfulness practices,
3. provide an opportunity for peer networking within a shared experience framework.

Cancer diagnosis and subsequent treatment is stressful, with reports of distress affecting approximately 30% of individuals across the cancer trajectory (Lambert, et.al, 2012) with some people experiencing a high level of distress after finishing treatment (Gao et.al, 2010). As an intervention ACT has the potential to improve the quality of life among cancer patients, entering the survivorship phase (Hulbert-Williams et al, 2015). Early studies with cancer patients have shown improvements in quality of life, distress, and mood (Feros et.al, 2013). Furthermore, peer support is considered an invaluable strategy in the survivorship process. Sharing a cancer experience with others has been identified as having positive outcomes such as helping develop effective coping mechanisms, improving emotional adaptation and wellbeing (Hoey et. al, 2008).

Post-program evaluations demonstrated that participants experienced positive outcomes from attending the group. In addition, qualitative comments confirmed the psychosocial skills acquired included outcomes such as feeling 'calmer'; 'more connected'; 'normal'; 'more in control' and 'looking forward to the future'. Feedback on the peer network component was positive, indicating long-term connections were established.

The program will be repeated with greater integration of strategies to expand the collection of data to further elucidate the importance of peer network support within a therapeutic support group format. This poster outlines the ACT Matrix used as the framework for group intervention which allows for unexpected and difficult conversations around survivorship issues to take place within a peer network model.

### **The Things that We Don't Talk About.**

*Author: Cheryl Butcher, Senior Social Worker, Wollongong Hospital.*

As Oncology Social Workers we work very hard to be able to provide the best Social Work response that we can within the Five Domains of Psychosocial Care – Physical and daily living, Psychological, Health Systems and Information, Patient Care and Support, and Sexuality. We also set out to meet the psychosocial guidelines for each cancer type, Lung Cancer, Pancreatic Cancer, Leukaemia, Breast Cancer and the list goes on. My Research seeks to look objectively at the patients at the Wollongong Hospital and the Wollongong Cancer Care Centre to see what may be hidden in the psychosocial demographics and statistics about them? What do patient charts tell us about the work that we have done? Is what we think that we are providing for Cancer patients the reality? Do we miss patients who have a high level of need? I believe that I may find that there has been many missed referrals. Now, that is something that I, as an Oncology SW, do not want to talk about. I also believe that patient's sexuality issues are being missed – do we want to talk about that? How many psychological issues have been missed? By looking at the psychosocial demographics of my patients, I am hoping to be able to find out and learn more about them. By looking at files, using data mining as my methodology, I will lay bare the work that has been done by Social Work in the Wollongong Hospital. How many missed opportunities will I find? How many patients have been missed by our Oncology Social Work service? We definitely don't like to look at this, however I am optimistic that we will also be able to learn from what we find in the psychosocial demographics to be able to fine tune our service provision. The information in our patient charts will also assist us to identify the things that we are doing well but more importantly show us the gaps in our service delivery. Although this is ultimately a good thing, when we are looking at the work that we do – it is definitely something that is hard to talk about.

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## **'All the things we talk about' – Enhance: Epworth's Multidisciplinary Breast Cancer Outpatient Rehabilitation Program.**

*Authors: Liz Alsop, Epworth Rehabilitation.*

This presentation will provide an overview of the breast cancer rehabilitation program that Epworth Rehabilitation offers across two of its sites in Melbourne. The presentation will focus on the role of social work in facilitating three sessions within the eight week group program. The presentation will also provide information regarding the benefits of the program, as identified by past participants, as well as the challenges associated with delivering the program from the multidisciplinary team's perspective.

The group is modelled on a multidisciplinary education and exercise format to address participants' individual rehabilitation goals. The group also encourages peer support. The program is a closed 8 week group and all participants are required to attend medical, psychosocial and physical assessments prior to commencing the program. Participants can also attend one-on-one allied health sessions to address needs that can't be met within the group sessions alone. The group takes a positive and strengths based approach as its theoretical underpinning, to support participants to move beyond treatment and towards important life goals.

The presentation will include an overview of feedback from past participants – all participants are given the opportunity to provide written feedback following the conclusion of each group.

The group format enables facilitators to bring a wide range of themes 'to the table' for exploration and discussion. In fact, there are no topics or questions deemed inappropriate and as such, this offers a contrast to the conference theme. Participants are encouraged, within the safe environment of the group, to raise concerns and questions relating to their recovery, rehabilitation and overall wellbeing. Discussions around self care, prioritising personal wellbeing and pursuing new and positive relationships and friendships are some of the positive themes explored by our participants.

## **Emotion Coaching For Parents in the Paediatric Cancer Population.**

*Authors: Ruth Granata, Emma Walkinshaw, Rebecca Summerill, Oncology Social Workers, Lady Cilento Childrens Hospital.*

Children rely on their parents to appraise stressors and evidence indicates that parents are integral to improving the psychological outcomes of their children throughout and beyond their cancer treatment (Hildenbrand, et al. 2014).

We plan to adopt a family partnership model (Nieto, Day, 2009) to implement a psycho-education group for parents. The aim of this group is to increase parental awareness of individual parenting and coping styles and to equip parents with skills in emotion coaching.

Research reveals that emotion related parenting strategies are associated with reduced post-traumatic stress symptoms (PTSS), and can facilitate resilience and post traumatic growth (Howard Sharp et al, 2017) in children. A key objective of our group is to teach parents how to recognise their child's emotional cues and to respond empathically to their child's emotional needs. In doing so, we hope to equip parents with the skills to engage in open communication with their children around their thoughts, feelings and fears and to "lighten the burden of secrecy for children" (Beale, Bail, Aaron, 2005) with a cancer diagnosis.

Theoretical basis: Parental Meta -Emotion Philosophy , Emotion Coaching (Gottman et al, 1997) Attachment Theory, Family Systems Theory, Family Partnership Model, Cognitive Behavioural Theory.

Outcomes:

- Increase parental efficacy to identify and respond to the emotional cues of their child.
- Provide parents with emotion coaching skills designed to improve their child's emotional regulation and competence,
- Harness children's emotional experiences as an opportunity for teaching and for strengthening the parent child relationship.

- Improve children's ability to label and express their feelings and fears and to discuss difficult topics and lived experience.
- Reduce child stress and anxiety throughout treatment, PTSS, promote positive post- traumatic growth and to enhance children's problem solving abilities.

The anguish of having a child with a cancer diagnosis is widely documented in medical and psychosocial literature, however practice wisdom in the paediatric oncology space, has revealed that the emotional needs of children often remained unexplored by parents. We envision that by providing parents the skills to identify and respond empathetically to their child's emotional cues, this will facilitate conversations around the 'things left unsaid' and will provide children with a voice in their cancer experience.

### **Paediatric Oncology Social Work: a new model of care.**

*Author: Janine Kemp, Social Work Clinical Lead, Lady Cilento Children's Hospital.*

Social Work has a long established tradition both nationally and internationally in providing universal psycho-social care to families attending hospital cancer services, with high quality evidence to support a strong recommendation for multi-faceted, systematic and consistent assessments of psychosocial health care needs of children/youth with cancer and their families as a standard of care in paediatric oncology. Social Workers operate from a biopsychosocial model, which views disease as an interplay between the environment and physical, behavioural, psychological and social factors. Social Workers assist individuals and families to maximise their functioning by targeting areas of difficulties and strengths in social systems.

The revised LCCH oncology social work model of care provides an opportunity to explore a more efficient and more systematic service delivery model that ensures social work services are delivered at the right time and are available to children and families as clinically indicated throughout the entire cancer experience, particularly at key trigger points.

The Psychosocial Standards of Care Project for Childhood Cancer (PSCPCC) 2015 provided a strong theoretical basis to inform the development of the new oncology social work model of care. Additional drivers included benchmarking with international and national sites, and collaboration with key paediatric psychosocial oncology experts and consumers (parents and young people) at the Paediatric Psychosocial Oncology Services Symposium Melbourne 2016. Key messages from this symposium included:

- Need to focus on the entire patient experience
- Need to integrate acute and community based care

Need to create a level of consistency within SW services to ensure equity for each family.

Outcomes:

- The establishment of an oncology social work service flow chart
- The establishment of an oncology social work patient spreadsheet to track the delivery of social work services according to the point of the cancer journey for each patient and family.

The establishment of the Oncology Social Work Assessment Tool (OSWAT): this tool is populated at end of two weeks post diagnosis and again at end of twelve weeks post diagnosis to determine level of service required - universal, targeted, or clinical psychosocial care. The tool was built around core components of psychosocial risk and key themes that emerged from the International Standards of Care.

In the previous model, there was a perceived lack of consistency and systemisation around required interventions and the level of psychosocial support each child and family should receive at critical points throughout the patient experience. The aim was to design a model that ensures high quality and consistent paediatric psychosocial support services throughout the cancer experience to improve patient care. The goal of this model is to provide a systematic approach so that all families can achieve improved equity and access to tertiary psychosocial care, and to provide a common language amongst the oncology SW team for the planning and delivery of psychosocial care to children and families.

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"I have been paddling and photographing for the past eight years. I was diagnosed with testicular cancer in 2010, had the tumour removed and soon after the termites resurfaced again six months later. I began paddling on the lake as a way to rebuild both my body and mind after enduring the intensive three-month bout of chemotherapy. I had never paddled a kayak prior to this and very quickly discovered how stunning it is to be on the water looking out – rather than looking in. You will find me paddling on Lake Burley Griffin and many other destinations most mornings and evenings, quietly snapping away at the unique seasonal and light changes that take place around me. Water and light are a beautiful combination and I find that this is my ideal place of peace and mediation. "

- Paul Jurak

Photographs used in our conference advertising and this program are courtesy of Paul Jurak.

