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Association of Respiratory Nurse Specialists

keeping you in up to date with the latest news in respiratory nursing

newsletter

Winter 2015

Welcome to the Winter edition of the ARNS newsletter

ARNS – Representing Respiratory Nursing 2015

This year has seen some new ventures for ARNS. After many years at the same venue in Warwick, we decided to embrace the geographical breadth of our membership and take conference 'on tour'. The result was a very successful trip to Belfast and a commitment to engage more actively with members from across the UK through the annual conference; 2016 will see us back in England but plans are already afoot to host the 2017 conference in Edinburgh. We are looking forward to meeting and sharing learning with respiratory nurses throughout the UK and giving members the opportunity to give voice to their thoughts and aspirations for best practice in respiratory care.



Social media platforms have really come into their own in recent years, with recognition that their impact is much more than just 'social'. Professionally, social media provides a forum for networking, discussion, sharing of ideas and models of practice and have enabled integrated working across national and international boundaries as well as the more traditional boundaries of organisations and professions. ARNS has a very visible presence in the respiratory online community as @ARNS_UK with monthly Twitter Chats that have generated lively interest in aspects of respiratory care. Twitter has a reach that most of us cannot even comprehend, with the November Twitter Chat on the COPD audit reaching almost 600,000 sharing ideas and examples of best practice. If you are new to social media, dip your toe in the water and find some interesting people to follow – you may find yourself having a remote conversation with someone whose work you have read about; it is a great means of leveling the professional playing field! Katy Beckford (@KatyBeckford) is ARNS social media lead and has played a key role in developing our online presence and website which is due to have something of a revamp in the near future, so expect some exciting new features over the next few months and years!

ARNS committee has also been instrumental in developing a respiratory virtual learning placement on the Nursing Times website, having identified a gap in the curricula of many student nurse training programmes, where woefully little time is available for respiratory nursing skills and knowledge. Patients with respiratory conditions present in all areas of healthcare and we hope that by providing some educational opportunity nurses may feel better prepared and perhaps develop an interest in respiratory nursing as a career pathway. We intend to continue to add content so if any members are interested in contributing please do get in touch with us via Twitter, the website or ARNS secretariat.

ARNS is recognised as a source of respiratory nursing expertise and regularly asked to comment on and contribute to strategic documents. In recent months members and committee have attended Parliamentary meetings regarding respiratory pressures on the NHS and the Lung Cancer report, we have contributed to NICE guidelines and consultation documents on respiratory medications, emphysema, pneumonia and palliative care and we have participated in the British Thoracic Society development

Continued overleaf...



of quality standards for home oxygen and pulmonary rehabilitation. We have represented respiratory nursing at European Congress and the e-cigarette summit and we have ongoing active involvement in the National Inhaler Project which has, to date, had notable success in influencing the policy decisions of the pharmaceutical industry regarding colour choice for inhaler devices. In this newsletter you will be able to read about members' experiences of attending an international respiratory meeting and participation in a NICE consultation process. Several members of the executive committee provide editorial input for respiratory content for a number of nursing publications.

We are pleased to welcome Lindsay Welch, from Southampton, to the committee; get a flavour for her working day in 'A Day in the Life', illustrating the variety that exists in Respiratory Nurse Specialist clinical roles.

ARNS, as an organisation, remains committed to representing the views of our members, who deal every day with the challenges that face those living and working with people with respiratory disease. The executive committee is keen to hear from you – consider submitting an abstract of your work to conference, write a practice reflection or clinical article, participate in online discussions and look out for the consultations we share with you. Consider applying for an ARNS bursary to support your attendance at a course or conference; revalidation begins next year and all of these activities provide opportunities for you to advance your practice and meet your professional development needs. We all know that patients and carers value the support of respiratory nurses; ARNS needs your help and participation to ensure that the voice of respiratory nursing, and so our patients, is heard on the wider healthcare stage.

Sandra Olive

ARNS works with Media Planet on Guardian Respiratory Supplement

Matthew Hodson and Wendy Preston, ARNS Chair and Vice Chair, recently worked with Media Planet Group to produce an article for inclusion in a Respiratory Supplement for the Guardian newspaper, which was published to coincide with World COPD Day on 18th November. You can read the article below, and view the full Respiratory Supplement via the website <http://www.healthawareness.co.uk/respiratory>

Lifestyle changes can improve hope for those with COPD

The hacking cough, another respiratory infection and ongoing breathlessness; what many people brush aside as 'old age' may well be the symptoms of chronic obstructive pulmonary disease (COPD).

The 'smoker's cough' has become part of our national vocabulary, but the phlegm-induced cackle is one of the most common symptoms of a disease that greatly reduces quality of life. More than a million people in the UK have been diagnosed with COPD and there may be as many as two million others who are living with the disease unaware. COPD is an umbrella term used to describe a number of respiratory diseases including, chronic bronchitis and emphysema, that can leave a patient struggling for breath and unable to carry out everyday tasks.

Roughly 80% of COPD cases are caused by smoking, although long-term exposure to dust and pollution, along with genetics, can also play their part. Over many years, smoking irritates and inflames the lungs and that inflammation leads the walls of the airways to permanently thicken and produce more mucus. In addition, damage is done to the delicate walls of the air sacs in the lungs, reducing their normal elasticity.

If the answer to this debilitating disease were just medication, it would be easy. But whilst inhalers and nebulisers can help alleviate symptoms in the short term, treating COPD requires patients to make big lifestyle changes, which is why organisations like the Association of Respiratory Nurse Specialists (ARNS) are encouraging patients to get treatment as early as possible. "More needs to be done to catch people early," says Matthew Hodson, Chair of ARNS. "If we can reach and diagnose more people earlier, we can get them onto the right course of treatment straightaway."

Peer Support

"The first thing we do is to help them stop smoking, if they've not already quit" continues Wendy, Vice Chair of ARNS, describing the course of treatment offered to someone with COPD. "We also ensure they have a flu jab, as consistent respiratory infections can exacerbate the problem, and we also offer them pulmonary rehabilitation, which is a combination programme of health education, exercise and support."

Wendy and Matthew both stress the importance of peer support to encourage lifestyle change, but when it comes to COPD, support groups are surprisingly different. Singing, it has been medically proven, can really help patients to control their breathing, so in hospitals across the country you'll encounter community 'singing for breathing' groups made up of patients with COPD and other respiratory conditions. In addition to the physical benefits, having the support of a group who are experiencing the same challenges can be hugely valuable.

However, "many people still only seek medical help when things reach crisis point," confirms Matthew. "For those with more advanced COPD, the trajectory is difficult to predict. There are so many different things that will impact their life expectancy." What is known is that quality of life will rapidly diminish as a patient's condition and symptoms worsens.

Those with advanced COPD are more likely to get respiratory infections and will certainly take longer to recover from them. Everyday tasks will become harder and over time many have to give up work. As a result, anxiety and depression are also prevalent. "People are often unsure what to expect as the disease progresses," says Matthew. "Decisions about future care are important and it's often easier to talk about them to healthcare professionals before someone becomes seriously ill."



A day in the life of Lindsay Welch

Southampton Integrated COPD Team Lead – Solent NHS Trust

I have discovered recently that flexibility does mean an ever adapting diary to maintain oversight and meet the needs of the patients, staff and stakeholders of an integrated service.

I have structured my week to mix clinical, operational, and managerial and a bit of research interestoh and a family life.

A typical Tuesday.....crow bar my children out of bed and try and talk my way out of cooking eggs for breakfast – unsuccessful – I have to cook, on the positive side I know the children will go to school on a full stomach.

I have to split my time between a community trust and the acute trust, Tuesday is the regular MDT meeting at UHS NHS Foundation Trust. The MDT include the COPD consultants, the team psychologist, the lead and members of the supported discharge/ in reach team, the team lead of Pulmonary rehabilitation from both trusts, plus nurses and therapists from both Trusts.

I walk my children to school and walk onto the hospital. MDT is the lynch pin of integrated working and I am keen for each MDT to be successful and provide the opportunity of every member of the service to present their patients; have a meaningful clinical discussion with peers and consultants and to leave with an action and a plan for that patient.

I chair the meeting in order to try and maintain a balance of patients presented and consultant and peer input. This week we discussed 2 patients that have been admitted twice in the last few months; frequency of COPD related admissions is a red flag for our service and would necessitate a more urgent consultant review. One particular patient is known well to the COPD service having been through pulmonary rehabilitation, and supported discharge. They were at a stable point in their disease, but sadly recently increased infection and decline in functional capacity have been noted and marked increase in anxiety and inability to cope with their breathlessness. This particular case is prompting a whole service approach to try and maintain stability for this patient and support them through their anxiety to manage their breathlessness, rather than calling 999. The team psychologist and the consultant plan to do a joint ward visit during this admission, also with family members. This may include an End of life discussion due to the continued functional decline.

MDT can take up to 2 hours depending on the volume and urgency of patients to be discussed.

After MDT the team leads, consultants stay with me to discuss staff turnover, staff development and any incidents within the teams. On a monthly basis, today this is a larger scale clinical governance meeting – enabling me to collate feedback, risk, and patients stories from each side of the integrated service. These meetings rotate to include a COPD service mortality and morbidity, audit and service planning.

Then is movement time, the last Tuesday in the month I cover the nurse led clinic in one of our 4 community venues. This venue is at the East of the city. I walk back home (very quickly) then drive for 20 min to the venue. I meet other staff members from Solent NHS community team; the exercise therapist and a senior nurse for the Pulmonary rehabilitation side of the service. We discuss the PR group they have completed and the list for this afternoon clinic. The consultant also has a local clinic list in the same venue, in order to offer all patients the choice of PR, and consultant care in their local area.

I have 3 patients on my list, one very complex patient who is struggling to move past the diagnosis of COPD and begin to work towards acceptance and life with a long term condition. Due to this they do not really wish to engage in smoking cessation or pulmonary rehabilitation. We talk about some of the small positive things we can achieve together today, I teach chest clearance and ACBT. They are however using their inhaled therapy; using an Incheck I test their inspiratory effort. It is a little poor, so we revisit inhaler technique and check all their inhalers are suitable for them based on their dexterity and inspiratory effort. We talk about managing breathlessness and setting small goals for every day. They agree to try these techniques for a month and come back – little steps in the right direction.

The last patient does not attend - this means I can eat something (about 3pm) and start to compile and write up the governance reports from earlier meetings – to feed into Solent Adult service Governance meeting the next day. I check and sign off health roster, adding on staff leave requests.

I start to compile and organise the ongoing audit for the Solent Long term conditions service line, this is a large job including audit work from other services. However compiling the audit together provides shared learning across the services and prevents repetition.

My children meet me at the health centre, they have eaten – but it is late and I am hungry. So we head home across the city.

Visit to Parliament for the British Lung Foundation Launch of ‘Tackling emergency presentations of lung cancer: An expert working group report and recommendations’



On the 3rd November 2015 I was lucky enough to be invited by the British Lung foundation to represent the Association of Respiratory Nurse Specialists (ARNS) to hear about their key recommendations from the working group to tackle the poor lung cancer patient outcomes in the UK.

As a specialist respiratory nurse it is important that this work is

recognised, promoted and supported to ensure that all lung diseases are highlighted, whilst I am not a Lung cancer CNS it's important that respiratory care is to recognise and remains in the spotlight within parliament to improve outcomes for all our patients.

What I was unaware of, before I attended the launch was that, compared to the European average, cancer survival in England is low. Lung cancer is the UK's biggest cancer killer, accounting for more than 1 in 5 of all cancer deaths. Dr Penny Woods, Chief Executive of the British Lung Foundation states that “despite claiming so many lives, lung cancer has not been given the prioritisation of other common cancers such as breast and prostate, something which is necessary if we are to tackle to poor patient outcomes that make the UK one of the worst places to have lung cancer in Europe, if not the world”.

Dr Tom Newsom-Davis, Chair of the Expert Lung Cancer Working Group, and Jane Ellison MP, Parliamentary Under Secretary of State for Public Health were among those presenting the recommendations and why they are essential.

In 2013, around 34% of all lung cancer patients were diagnosed via emergency routes, compared with 20% of other cancers. This was surprising to me as someone who does not work in this field, I have always assumed that patients were identified and treated quickly and appropriately.

This is not what is happening. Many patients are going to their GPs too late when their persistent cough is troubling them. The GPs are finding it hard to communicate with secondary care and to also get access to CT scans.

The key recommendations aimed to improve this are:

Recommendation 1. Funding for a National campaign (such as Be Clear on Cancer, Detect Cancer Early or Be Cancer Aware) be maintained or increased, in order to raise awareness of the signs and symptoms of lung cancer

Recommendation 2. A commitment be made to rapid adoption of a targeted evidenced-based lung cancer screening programme, as deemed effective by the UK National Screening Committee, in order to reduce the number of lung cancer patients diagnosed late and via emergency routes.

Recommendation 3. Lung cancer risk assessment/clinical decision support tools be tested and the most effective be made available in all primary care practices. Appropriate support be provided to enable GPs to utilise these tools at practice level and, where possible, a scaled-up version should be made available at CCG level.

Recommendation 4. If proven effective and feasible, rapid access outpatient pathways should be introduced to prevent unnecessary emergency admissions.

Recommendation 5. A timed pathway for patients with suspected lung cancer admitted as an emergency, from time of initial presentation. This would include:

- Seeing a member of the Acute Oncology Service of Lung Team within 24 hours
- A CT scan conducted within 48 hours
- Review by the lung multi-disciplinary team (MDT) within a week
- Being seen by a member of the lung MDT within a week

Recommendation 6. GPs be able to make direct access referrals for CT scans for patients with suspected lung cancer

Recommendation 7. All chest X-Rays and CT scans be formally reported

within four days. The individual requesting the x-ray must acknowledge and act upon the result. Local mechanisms should be in place to ensure scans which suggest a possible diagnosis of lung cancer trigger referral to a Specialist Rapid Access Lung Cancer Clinic.

Recommendation 8. Direct telephone or email access between GP practise and secondary care consultants to speed discussion about high risk cases.

Recommendation 9. Centralised systems be set up, either at GP federation, CCG or regional levels, in order to ensure data can be shared.

Recommendation 10. A Clinical Nurse Specialist (CNS) be available to all patients undergoing investigation for suspected lung cancer

Recommendation 11. All patients diagnosed in an emergency setting be seen within 24 hours by an Acute Oncology Nurse, who then acts as the

patients key worker until they are safely handed over to the appropriate CNS. As Dr Penny Woods states, 'it is time for lung cancer patients to be prioritised and for the stigma associate with the disease to be overcome'.

Improved communication, access to services and referral pathways and improved links to Clinical Nurse Specialists will go a long way to improving the outcomes for Lung cancer patients in the UK.

As a specialist nurse I found this key recommendation to be the most powerful for me. We know that CNS's make a significant difference to the care and lives of our patients and it was great to see that recognised in this document and that the need for more specialist nurses in this area is vital.

Katy Beckford



My experience of attending the European Respiratory Society Annual Conference.

I can still recall the first time that I was sponsored to attend an ERS conference. I was so excited, firstly as I had never attended anything in another country to do with work before and secondly for the immense learning opportunity that it was going to afford me. That was several years ago now, and I have to say that I have been very fortunate indeed to have attended every conference since, only missing one year.

The one thing that sticks in my memory from that first visit was the sheer scale of the conference from the amount of delegates attending to the amazing organisation of the ERS, sessions ran like clockwork. I can also recall thinking "this is the who's who of the respiratory world". People whose research I had previously only read on pages of a journal were now standing in front of me presenting new data and discussing all things respiratory. I have to admit I was a tad star struck by it all. I also remember being made to feel so welcome by all I encountered and still have that feeling every time I attend, it's like meeting up with family once a year and catching up. The networking experiences are invaluable and I learn just as much from colleagues across the UK as well as other countries along with attending the formal sessions.

I would say however that I was totally unprepared on my first visit, and have since learnt that the key to having a good conference is forward planning, and a good pair of walking shoes! I now study the programme in advance and choose the sessions that are relevant to me and that I feel I can learn from in order to return to my clinical workplace and start to make changes to better the lives of my patient, their families and carers, as that is ultimately what we are all trying to achieve.

I would thoroughly recommend that anyone who is offered the opportunity to attend this conference do so as I have no doubt that you and your patients will benefit from it.

Natalie Harper

ARNS Annual Conference 2016 22nd and 23rd April, 2016 - Loughborough

The 2016 ARNS Annual Conference will be held on 22nd and 23rd April at Loughborough. We are delighted to announce our keynote speaker will be Jane Cummings, Chief Nursing Officer for England. Please add this important date to your calendar. Registration forms can be downloaded from the ARNS website: www.arns.co.uk



Representing ARNS at a NICE Scoping Workshop and Consultation

Susan Perrott MSc, BSc, RGN
Respiratory Specialist Nurse - Cambridge University Hospitals Foundation Trust

In the September News Letter there was a 'call to arms' for a member to represent ARNS at a NICE Draft Scope Consultation and Workshop to consider an appraisal of human alpha 1-proteinase inhibitor for emphysema. As I have an interest and specialist knowledge in alpha 1-antitrypsin deficiency I volunteered for this task. Part of my Respiratory Specialist Nursing role at Addenbrooke's Hospital in Cambridge incorporates supporting the regional Alpha 1 Antitrypsin Deficiency Service which has given me the opportunity to understand how this disease can affect people's lives and the impact it has on their families.

I have been asked to write a short resume of my experience. It took me some time to understand what a Scoping Workshop and Technology appraisal involved but once I had my head around the terminology I felt slightly more confident about attending the meeting on the 16th October 2015 in the NICE offices in London.

To give you a bit of background to the story so far - following the recent publication of a paper on the RAPID trial (Chapman et al 2015) in The Lancet, which involved the Alpha-1 (AAT) augmentation therapy Respreeza, and the European Medicines Agency's recent approval of Respreeza for prescription in Europe, the National Institute for Health and Care Excellence (NICE) is currently considering a technology appraisal of this augmentation therapy to develop recommendations on its use in England. The RAPID trial provides evidence that purified A1PI (α1 proteinase inhibitor) augmentation slows progression of emphysema and suggested that these findings should prompt consideration of augmentation treatment to preserve lung parenchyma in individuals with emphysema secondary to severe α1 antitrypsin deficiency.

The scope of this potential health technology appraisal has been under consultation with different stakeholder groups in the UK and a comprehensive list of Consultees formally responded in detail to the NICE draft scope consultation and along with myself some of these Consultees attended the NICE scoping meeting. The aim of the meeting was to discuss with stakeholders - including clinicians, professional groups, patients, patient support groups, industry, NHS England Specialist Commissioning and the Institutes project team - the most appropriate scope for a potential technology appraisal for augmentation therapy. In other words the scoping workshop was there to review the Draft Scope prior to the NICE technical team making a well-informed recommendation to Ministers. Ministers will then decide whether and how augmentation therapy should be appraised by NICE.

I found this initially quite a challenging experience due to terminology and process which was novel to me but it was a useful opportunity to gain first hand insight into how NICE project teams support decision making particularly in rare disease management when expensive technologies and specialist commissioning is involved. My knowledge of this cohort of patients enabled me to support the patient groups with some of their concerns regarding lack of specialist knowledge amongst clinicians and highlighted to me the requirement for more education around early identification of α1 antitrypsin deficiency plus a need for specialist support networks for both patients and clinicians who infrequently manage this rare disease.

Reference: Chapman, K. Burdon, J. Piitulainen, E. et al (2015) Intravenous augmentation treatment and lung density in severe α1 antitrypsin deficiency (RAPID): a randomised, double-blind, placebo-controlled trial. Lancet 386 (9991). p. 360-368



The above companies have provided sponsorship grants towards the conference, secretariat, mailings, newsletters, website maintenance and educational bursaries of ARNS