

[View in browser](#)



Carmarthenshire Disability Coalition for Action NEWS LETTER

February 2022

1. Recording PIP assessments.
2. Wales Co-operative Centre - Winter Hardship Project.
3. The secret report was published.
4. Rheumatoid Arthritis treatment.
5. Preparing for a Big Changing Places Year.
6. National Disability Strategy.
7. High Court rules Dido Harding and Mike Coupe appointments were unlawful.
8. High Court rules against legacy benefits claimants.
9. The Wrong Wheelchair. (A Wallace & Gromit parody)

CDCfA Newsletter back issues can be downloaded from our [Website](#).

Recording PIP assessments

A regularly recurring theme is that of assessors misrepresenting what they have been told by claimants. An obvious solution is recording the assessment - but this has been fraught with difficulty, as official guidance was that claimants had to use a dual tape recorder so that both parties would have identical copies. Way beyond the means of most people.

Perhaps bowing to the inevitable, the DWP now allows recording on a mobile phone.

New guidance issued to health professionals

Of course, the burden could be removed from claimants if they were confident that the assessor would record their encounter, and not misplace the recording subsequently.

One of the companies subcontracted by DWP to carry out assessments (IAS) started making audio recordings in September 2020 but the other, Capita, dragged its heels. So claimants could not be sure that there would be a recording available, either for use at any future tribunal or simply for their records.

The new guidance says that providers have the facility to audio record telephone and face to face consultations and that this should remove or reduce the need for claimants to record consultations.

Claimant recordings are entirely lawful

So - you can ask in advance for your assessment to be recorded, and it should be done.

If you want to make your own recording on your phone, just in case, it is completely lawful for you to do so - for your own information, to share with an advisor or use as part of an appeal.

In either case, you will be asked to give your agreement not to use the audio recording for any unlawful purposes, by signing a consent form if it is a face-to-face assessment or giving verbal agreement over the phone.

You can download the government guidance to professionals [here](#).

Wales Co-operative Centre - Winter Hardship Project

The aim of the Winter Hardship Project, funded by the Welsh Government, is to support hospital leavers who are at risk of digital exclusion. Being digitally excluded means that someone doesn't have the skills or confidence to use technology or that they don't have access to the internet.

Organisations can apply on behalf of a specific individual at risk of digital exclusion for up to £500 for a digital device and/or connectivity. For more information on how you can access this fund; <https://wales.coop/winter-hardship-project/>

The secret report was published

The Work and Pensions Committee has achieved its promised aim, by making public on their own webpage "The Uses of Health and Disability Benefits", the DWP-commissioned report which the Department has refused to publish in the usual way. [You can access the full report here](#).

Rheumatoid Arthritis treatment

How much attention do you feel your doctor pays to your concerns about treatment?

A recent survey of patients with rheumatoid arthritis (RA) found that 40% felt that they were not really listened to when it came to treatment plans - and a shocking 70% discontinued what is currently the "Gold standard" treatment for RA, suggesting that there is something badly wrong with the current system.

National Rheumatoid Arthritis Society survey of patients

New data from rheumatoid arthritis patients reveals that 62% suffer significant negative quality of life issues, affecting their relationships and work in particular, and over half do not take their treatment as prescribed.

Alarming, more than 70% of all RA patients prescribed a first-line oral treatment, as recommended by NICE, stopped taking their treatment completely, with 54% citing unpleasant side effects as the main reason.

Results from the survey suggest that such poor adherence is linked to the lack of patients' understanding of, and involvement in, their treatment choice.

Clinical Nurse Specialist in Rheumatology, Tracy French:

"As time with a consultant can be so limited, it can be difficult for patients to understand everything they need to know about their treatment to ensure they choose one that best suits their needs and lifestyle"

In fact, consultation times were found to be less than 30 minutes for two-thirds of RA patients and over half of the patients would have liked more information about their proposed treatment.

40% of patients also felt as though their opinions and concerns had little to no influence on their treatment choice. Perhaps not surprisingly those who had a longer consultation, and were provided with more detailed information, reported having a more positive response to their treatment.

Tracy French again:

“Simply understanding more about their treatment, how it can be administered, as well as the potential side effects and benefits can dramatically improve adherence and provide better symptom relief, so I advise my patients to ask as many questions as they can in their consultation”

Less than one in 10 patients given a choice

In the recent survey, only 9% of patients were given a choice of how they'd prefer to take one of the most common treatments for rheumatoid arthritis which can be administered in different ways with differing side effect profiles, dosing levels and efficacy rates.

However, nearly half of patients who later switched from an oral tablet to an injectable device for the same medication felt that it had had a positive impact on their quality of life. They reported a 42% reduction in side effects and a 40% reduction in symptoms and would have preferred the injectable route if they had known about it at the start of their treatment.

Introducing the ASK approach

Following these survey results, leading rheumatoid arthritis experts are encouraging patients to adopt the 'ASK' approach to consultation, empowering them to make informed decisions for a better treatment experience.

- Address your main concerns at the start of your consultation
- Share details of all symptoms with your consultant, prioritising the most detrimental to your quality of life
- Know as much as you can about your prescribed treatment, including what format you can take it in, potential side effects, how long it can take to work and other options if it fails to work

Clare Jacklin, CEO of NRAS adds:

“These results show how important it is for patients to understand the benefits and side effects of treatment. Knowing all the options and feeling involved in the treatment decision-making process is shown to result in better adherence and improved symptom relief. This is where NRAS can offer help and information. Many calls to our helpline are from newly diagnosed patients who can really benefit from being put in touch with our Here For You volunteers who can share their experience of living with RA and taking medication etc. The lived experience can help to allay worries and anxieties hence improve adherence to treatment.”

More information on RA treatment options is available on the [NRAS website \(www.nras.org.uk\)](http://www.nras.org.uk), in addition to patient support and resources (external link will open in a new browser tab or window).

Ed. While attending an appointment at Glangwilli Hospital in January I noticed a mobile Osteopathy Unit at the Out Patients entrance. I was troubled by the access to the unit and I established there was no ramp or lift access which made me think that they were a bit 'OUT OF TOUCH' with the condition of people who might want to visit the Unit. What do you think?



Preparing for a Big Changing Places Year

Changing Places toilets have become a more commonplace sight across the country and the supporting campaign is now nationally recognised. A lot of this recognition has come over the last couple of years, thanks to funding boosts, legislation changes, and the determination of so many campaigners.

2022 sees the £30 million investment promised by the government start to arrive in local authorities' accounts, so it's likely to be a busy year indeed. Modular Changing Places - high-spec prefabricated units that come fully kitted out with the necessary equipment - are increasingly popular with councils, who can see new facilities delivered and installed within days.

National Disability Strategy

The National Disability Strategy sets out the government's vision to improve the everyday lives of disabled people. We want to ensure that disability is not a barrier to people living full, independent lives where they can reach their full potential.

The strategy has been developed with the input of more than 14,000 disabled people, as well as disability organisations, businesses, policy experts and many others.

In this publication, departments and agencies in every corner of government set out how they will help bring about practical and lasting change to disabled people's lives.

Part 1 sets out immediate commitments we will make to improve every part of a disabled person's day.

Part 2 sets out changes to how we will work with and for disabled people into the future, putting disabled people at the heart of government policy-making and service delivery.

Part 3 summarises the actions each government department will take, with ministerial champions setting out their personal commitment to the strategy.

[National Disability Strategy: web-accessible PDF](#)

[National Disability Strategy: Easy Read](#)

[National Disability Strategy: large print](#)

[National Disability Strategy: Welsh translation](#)

From:

[Disability Unit](#), [Equality Hub](#), [Department for Work and Pensions](#), [Justin Tomlinson MP](#), and [The Rt Hon Thérèse Coffey MP](#)

Published

28 July 2021

High Court rules Dido Harding and Mike Coupe appointments were unlawful

In a landmark verdict, the High Court has today found that the process leading to the appointments of both Dido Harding and Mike Coupe was unlawful. It held that Matt Hancock broke the law in appointing Dido Harding as Chair of the National Institute for Health Protection (NIHP) and in appointing Mike Coupe as Director of Testing at Test and Trace (NHSTT). The High Court was also clear that the Prime Minister broke the law in appointing Dido Harding as Chair of Test and Trace.

The Court declared: "The Secretary of State for Health and Social Care did not comply with the Public Sector Equality Duty in section 149 of the Equality Act 2010 in relation to the decisions on how to appoint (i) Baroness Harding as Interim Chair of the National Institute of Health Protection in August 2020 and (ii) Mike Coupe as Director of Testing for NHS Test and Trace in September 2020."

While the formal declaration reflects only the appointments made by Matt Hancock, the High Court is clear that the process adopted by the Prime Minister was also unlawful (paragraph 116). All three appointments breached the public sector equality duty.

In reaching this conclusion, the Court accepted the argument made by race equality think tank the Runnymede Trust and Good Law Project that the recruitment process adopted by the Prime Minister and the Secretary of State ignored the need to eliminate discrimination against the country's disabled and ethnic minority communities, and to ensure they have equality of opportunity.

In appointing the wife of Boris Johnson's Anti-Corruption Tsar John Penrose MP to Chair the National Institute for Health Protection, the Government failed to consider the effects on those who, the data shows, are too often shut out of public life. The Government also ignored its own internal guidance, which requires Ministers to consider how discrimination law will be complied with.

The Runnymede Trust and Good Law Project brought the case to highlight what it means to disadvantaged groups for the Government to push its associates and donors into key jobs. The Court's declaration will have a real impact on how public appointments are made in the future.

The Government must now take seriously its legal and moral obligations to narrow the disadvantages faced by people with disabilities and those of colour. Public appointments must not be made without taking steps to eliminate discrimination and to advance equality of opportunity, even when normal processes don't apply, for instance during a public health emergency. The

Government will now have to be much more careful to make sure its recruitment processes are fair, equitable and open to all.

Read the High Court's judgment [here](#).

High Court rules against legacy benefits claimants

The High Court has decided the Department for Work and Pensions (DWP) did not act unlawfully by denying nearly two million disabled people emergency funding to help them survive the pandemic.

At the beginning of the pandemic, people on Universal Credit were given an emergency increase of £20 a week. But disabled people on legacy benefits, including many with MS, were left behind.

Legacy benefits include Employment and Support Allowance and Income Support and will eventually be replaced by Universal Credit.

The case brought to the High Court

In November 2021, four legacy benefit claimants brought a case to the High Court. The case stated the Government had acted unlawfully by denying nearly two million disabled people on legacy benefits the same emergency increase of £20 per week that was given to those on Universal Credit. The decision resulted in an increasing number of disabled people struggling to afford food, rent and medication.

Groups gathered outside the High Court included members of the Disability Benefits Consortium (DBC), MS Society and Disabled People Against Cuts (DPAC). They stood in solidarity with everyone who had been denied the extra financial support and demanded justice. Three months after the hearing, the judge has finally made a ruling in favour of the DWP.

*Ed. For a country that claims to have adopted the United Nations Convention on the Rights of Disabled People (UNCRDP), we seem to have a very poor track record on how we treat our disabled community. It is deeply disturbing that this fundamental case was lost as it casts a shadow over the action of standing up for the Rights of Disabled People. **More Disabled People need to Get Up and Stand Up for their Rights.***

The Wrong Wheelchair. (A Wallace & Gromit parody)

This is a true story. The scenario; a couple, Mr & Mrs X, Mr X is disabled having lost the use of one side of his body and Mrs X is his carer. Mr & Mrs X are the opposite of the humorous Blackpool postcard couple, she is quite small and demure while he is quite large and portly. They apply for a wheelchair so that she can wheel Mr X around when they go to the shops and are invited for an assessment at a well know Artificial Limb and Appliance Centre (ALAC) in Morriston.

ALAC have rules the sanctity of which may not be challenged. ALAC tell Mr & Mrs X that people who are unable to self propel can not have a standard wheelchair. Mr X must have a wheelchair with four small wheels because Mr X can not self propel.



The Small Wheel Wheelchair

For people who can not self propel

Mr & Mrs X go home with their small wheel wheelchair but within the month they have returned to ALAC with tails of woe. Alas Mrs X is not strong enough to pull Mr X up kerbs or the lips of doors or any other obstruction generally found in the everyday environment, but they have tried using a standard wheelchair with great success as Mr X, despite only having the use of one side of his body, is able to assist when they encounter an obstruction.

So Mr & Mrs X asked ALAC, "Can we have a standard wheelchair please?" Alas and alack no you can not say ALAC. Mr X can not self propel so you are not entitled to have a standard wheelchair. You must use a small-wheeled wheelchair.

The conclusion of this tale is that Mr and Mrs X had to purchase a standard wheelchair and the small-wheeled wheelchair now lives in a shed at the bottom of the garden.

I have a question for ALAC at Morriston Hospital. "How does this fit in with the Senedd's recent directive about reducing the barriers faced by disabled people in Wales?"



The Standard Wheelchair

For people who can self propel

Carmarthenshire Disability Coalition for Action
Coleshill Centre
Coleshill Terrace
Llanelli. SA15 3BT
office@cdcfa.org.uk



This email was sent to {{ contact.EMAIL }}
You received this email because you are registered with Carmarthenshire Disability Coalition for Action

[Unsubscribe here](#)

